Lived Experience Collective

Spring 2026

The Lived Experience Collective (LEC) was created in 2024 by the Connection Learning Healthcare System (CLHS), one of eight hubs of the Early Psychosis Intervention Network (EPINET).

The LEC is made up of current and former participants of coordinated specialty care programs in Pennsylvania and Maryland. The LEC also includes members from the Lived Experience Integration Team (LEIT), made up of researchers and peer support specialists.

One of the main roles of the LEC is to give consultations on grant-funded research projects by CLHS. When not consulting, the LEC works on various projects they hope to share with the larger community to make a positive difference in fellow peers' lives.

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Meet the LEC

Who are you outside the LEC?

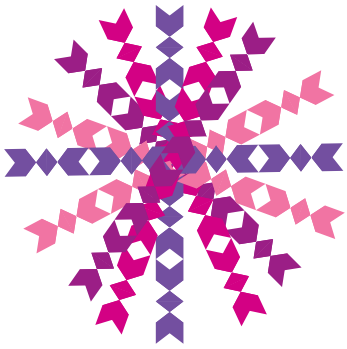
- *"I am an artist. I have friends and create through my static thoughts. I am also a son, uncle, brother, and advocate. I love walking to clear my mind after a long day."*
- *"I am a daughter, aunt, cousin, and a worker. My lived experience does not define me but enhances me as a person. I am someone who loves to create art, throw parties, garden, and enjoys laughing."*

What does being a part of LEC mean to you?

- *"Being a part of LEC means that the world knows that there's a group created for us."*
- *"Helpful, as it is a space that is collaborative and supportive of one another's journeys."*
- *"The LEC means to me HOPE for positive change, and connection to people who have similar experiences."*

What have you gained from participating in meetings?

- *"I've personally gained a lot of insight and a lot of other viewpoints from like-minded individuals."*
- *"Connects; kind interactions; sincere understandings of one another. Great ideas of ways to help one another."*
- *"I have gained a reminder of how far I have come, and that I'm not alone... a space to voice my experience and share with others."*
- *"[It's] been great learning about other people's viewpoints and finding out where we share similar goals. Everyone has so many amazing ideas."*



Dreams to Come

"My hope for the LEC is for it to grow to a larger space, so it can have more capabilities...I also hope the LEC will eventually get more participants so we can continue to share and grow shared experiences."
— LEC member

One of our main goals is connecting with more researchers in the field so we can consult on a greater variety of projects. We want to bring out unique perspectives into the important research happening to improve outcomes for fellow peers.

Between our consultations, the group discusses other ways we can live our values and make a difference in the community. Here are some of the projects we've been working on and hope to bring to fruition.

Sharing Experiences of Psychosis

It can be lonely when discovering we don't quite fit the model of "symptoms" being taught by psychiatry. Yet, the more we learn how unique we each are, the more we can own our stories, our struggles, and our triumphs. Our hope is to spread this awareness deeper into the community so we can all gain strength from our differences.

Anti-Psychotic Medication

Our experiences with medication, including anti-psychotics, are diverse. Often, the side effects make taking medication challenging or unsustainable. We will be presenting on this topic at the International Society For Psychological and Social Approaches to Psychosis (ISPS) 2026 conference in July so we can reach providers and psychiatrists and broaden the conversation surrounding medication. Let's elevate the voices of people prescribed medication so that they feel self-empowered to make the best decisions for themselves.

Supporting Self-Care

Youth are often overwhelmed by expectations: the pressure of assignments and grades, worry about college or trade school admissions, the search for identity, and taking the first steps into the workplace. And that only scratches the surface of pressures we face. There's also the everyday balance of our lives outside of home, with extracurriculars and social responsibilities, and our home lives and responsibilities to our families.

Those with lived experience have had to work hard to learn how to do self-care every day so as to heal and get back on our paths. This unique perspective is invaluable for any young adult regardless of background and the LEC aims to deliver that perspective to those who need it.

Psychosis Experience

"I really struggled to explain my experiences. Every time I tried, it felt like they were reduced to something I disagreed with... I was told any emotion was only a symptom and therefore felt invalidated."

"A lot of my extreme beliefs were hard to describe to people (delusions, paranoia.) It was hard to talk about it because of how others would react.... My treatment was about getting rid of it, and understanding it was wrong/ bad which felt dismissive of the impact on my life."

"I found lots of meaning from many of my experiences, and found it distressing and harmful how little anyone else wanted to hear about that meaning."

"I'm misunderstood with negative symptoms of psychosis as I may come across as unable to care about other people's feelings or if I have low energy levels ..."

"I would describe my experience as my whole world shutting down and enclosing on my mind and feelings. Put into a box with minimal connection to the outside world. Secluded and distorted state of consciousness."

"In my experience in having altered states during times of distress it feels as though the world is ending and it's all because of me. For example it's like an abandoned amusement park."

"No one seemed to care about talking to me about the nuance of my experience. Navigating taking accountability for my actions in psychosis while recognizing I wasn't fully myself is an ongoing difficulty."



"Sometimes it's hard to distinguish between reality and fiction while experiencing symptoms."

"Now that I am doing a bit better, how much I have been impacted by psychosis and how hard I try to appear 'normal' are consistently not understood."

"For me, I experienced a lot of different time and spacial alterations. I would experience time skipping, or objects changing texture/shape as I was looking at them. Or facial expressions suddenly contorting in front of my eyes."

LEC Member Testimonies

Being part of the Lived Experience Collective meetings has been very impactful. Participating in the LEC has been a valuable investment in my mental health journey. I believe that in the coming years, we will see better treatments and medications for severe mental illnesses, thanks to the discussions we hold every month. Everyone has been incredibly supportive and welcoming, making everyone, including myself, feel a sense of belonging. I've been on my mental health journey since I was first diagnosed with schizophrenia spectrum disorder last year, and it has been eye-opening. I went through years of active psychosis without realizing it. I used to think my experiences were just part of growing up. After my psychotic break, I was evaluated at an inpatient hospital and received treatment. Little did I know, just a few days later, I'd be diagnosed with schizophrenia.

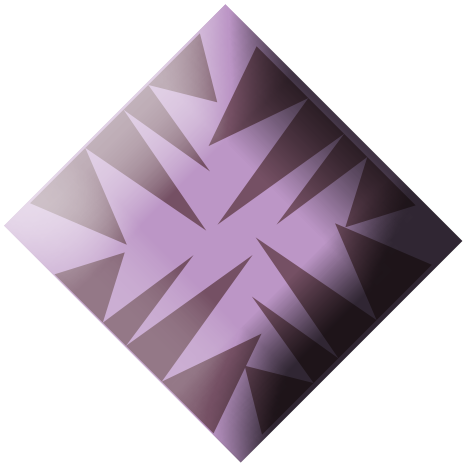
The diagnosis itself didn't surprise me, but it made me curious and grateful to know I wasn't alone in feeling and enduring these experiences. Once I was well enough to be discharged (I was on an extremely high dose of anti-psychotics) and before starting inpatient treatment, I decided to reduce my medication by 8 mg because I felt like a complete zombie.

Since then, I've been very consistent in taking my medication daily without relapsing, and I'm thankful for the advanced treatments and opportunities provided by my medical professionals. As a result, I was able to complete my bachelor's degree and I'm now looking forward to continuing my education as my mental health improves. Now, I am on a mission to support anyone and everyone with severe mental illnesses to feel less alone in the process.

The stigma surrounding schizophrenia has deep historical roots, shaped by centuries of misunderstanding and fear. Early ideas depicted individuals as morally deficient and dangerous, often using bizarre beliefs and explanations to

justify the inhumane institutionalization of those affected. Although practices and views have improved over time, harmful attitudes toward schizophrenia persist, reinforced by media portrayals and cultural narratives linking active psychosis with violence. Research increasingly shows that stigma is widespread, especially within healthcare settings, where avoidance behaviors include implicit biases and therapeutic pessimism. Alarmingly, these attitudes are not limited to general healthcare providers; even mental health professionals, who are most involved in supporting individuals with schizophrenia, can perpetuate stigma through overt or subtle behaviors, such as adopting overly paternalistic approaches, underestimating patients' abilities, or failing to examine their own biases.

Understanding how stigma varies by provider group, and the factors that shape these differences, is critical for developing targeted, sustainable stigma-reduction efforts. Differences are probably given variations in training, patient contact, education, and professional roles. For example, a healthcare provider working within a recovery-oriented framework that promotes self-efficacy, and who has observed positive patient outcomes over the years, may differ significantly from someone with little experience working with schizophrenia who takes a strictly biogenetic perspective. With that being said, stigma is highly prominent, but with more and more people coming out and sharing their stories, it should decrease as more of the public becomes aware of successful stories.



LEC Member Testimonies

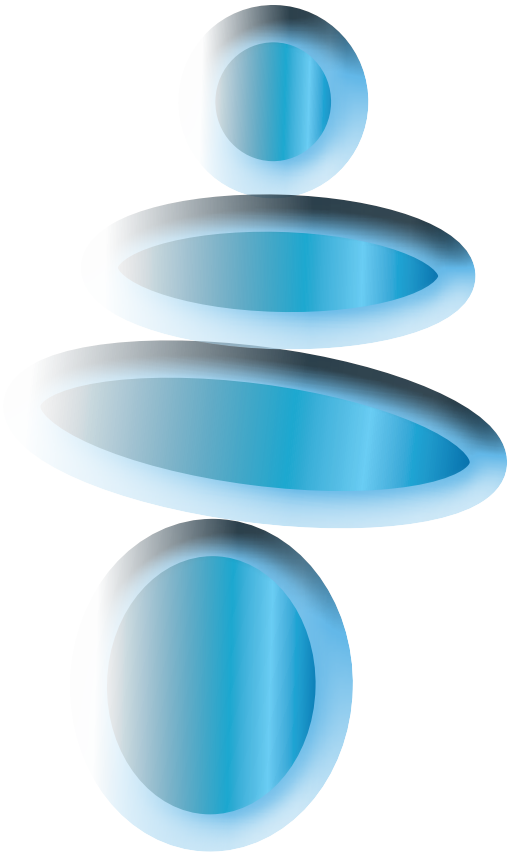
Being in the CSC and LEC programs and participating in these therapeutic virtual appointments has been very meaningful and helpful. I recommend this because it's a good way to express yourself, get the self-care you may need, and also earn a little extra money for those who are employed or unemployed. The program itself compensates you while helping you gain a broader understanding of what people with different disabilities experience in their daily lives. What I have gained from these virtual meetings is that, although nobody is 100% the same, I'm not alone in this battle with schizophrenia.

When I was first diagnosed with psychosis, I didn't think a bright future was possible. I thought life was over, and there was no hope for anything good to happen anymore. Through programs like LEC and the PEACE program, I was comforted and therapeutically reborn into a new life of living with a disability. I literally had to take everything I learned and relearn it differently, through a new perspective on life.

Mental health can be quite challenging if you don't seek and get the proper help you need. It can be even more difficult if you try to handle all your problems by yourself. Through my journey, I have learned that having a family you can count on, whether blood relatives or friends and acquaintances, can be very helpful, even if it doesn't seem that way at first. You may feel like no one understands you until you meet people like you, and give people a chance to share parts of themselves that you may have previously misjudged or not fully understood. Once you surround yourself with people who can uplift you instead of drag you down, you see life in a whole new way. Self-care is very important when it comes to mental health because nobody knows you like you know yourself.

LEC has been very helpful because it has helped put money into my pocket while helping give a mental break, especially when there was no income being made. I can see the participants and workers continuing to help one another

with the socialism, while helping get the "drawing board" of the newsletter as strong as possible, while giving participants an incentive. I think this is a good relationship because, though not technically being employed, it gives people motivation to want to "scratch each other's back". Our communication directors... help us to express ourselves wholeheartedly, being honest and being unguarded about our feelings. Here, there is no blatant judgment or negative views about someone just because of what they're going through. I enjoy when other peers share their opinions and the way they live their lives, too. Nobody is perfect, and just because you have disabilities and see the world differently than others does not mean you are any less, and this program reassures that. I remember starting with my symptoms and feeling like there was no one else that could relate to me, but having experienced PEACE and LEC, I see that that was not true, and I look forward to hearing more people's perspectives and aspirations for life in the future.



LEC Member Testimonies

I have pieces of memory during my psychotic episode. It was one of the worst experiences in my life. To this day, when I recall the things I heard and saw during that time, I get chills and am transported into a dark mental state. Without my family, friends, and the CSC program, I would not be where I am today. I remember leaving the hospital feeling lost, confused, and dazed. I was embarrassed and did not know how to proceed in the world with this new diagnosis and experience. I have Bipolar [disorder]. I have stayed at a mental hospital. I did not want to accept my new reality. The following days, weeks, and even months were a hard time. I was determined to prove to people that I am okay and still the same old me.

However, I was not okay. I was not the old me. I have changed. I was in a depression for a very long time, part due to my mental health and part due to my life circumstances. It was not until I made some hard decisions in my life that I started to live. I started to accept myself. I started to love and take my life seriously. I wanted to be happy. I had dreams and goals that I wanted to achieve. I no longer wanted to live in the past, reminiscing on the old me. I had to focus on the present and the future.

I had to realize that I am still worthy. I am still capable. I am still smart. I am still kind and caring. None of those values changed because I am now Bipolar. So, I went on a journey. A journey of self-healing and self-discovery. I wanted to heal wounds that affected me and no longer served me. I wanted to change my ever-dying need to please and have people accept me. I wanted to be fearless and not be concerned if I fit in. What started to matter to me is that I loved and accepted myself for who I am—that is good enough.

I have always had many interests and hobbies, but after my episode, I lost the joy and happiness I had while doing them. I wanted to find the joy and happiness I once had while I experimented with photography,

sewing, making tea, and cooking. I also wanted to try new hobbies. I started painting, event hosting, interior designing, and taking my beauty routine seriously.

I love learning. I have always wanted to pursue higher education, but after my diagnosis and episode. I lost all confidence. I started doubting myself even more. I thought being Bipolar affected my mental capacity. However, my psychiatrist pushed me and gave me the confidence to pursue my goals. She made me realize that just because I am Bipolar, it does not mean I am stupid. Thank you, Dr. Mayanil. I will never forget the motivation and courage you gave me when I needed it the most. With her, my family, and friends, I went back to school. I worked to support myself and pay for school. I graduated with my bachelor's degree, then I took a break from school. I went back to get my Master's.



LEC Member Testimonies

My experience in mental health has been an assignment of mental fortitude and self-reliance. I have been in many hospitals over the course of my life. Throughout my time both in and out of the clinics, I have experienced a lot of both good and teaching events. While beginning my mental health journey, I had very little to no explanation to how or why my mind's synapses were malfunctioning. The cause, I know now, was a combination of bad habits, such as poor diet, environmental pressure, and, most of all, the intrusion of outside thoughts in my mind.

The constant influx in what I was feeding my mind made me more and more overshadowed. The bad thought[s] of others' view[s], the imposed position of where I had to be in life, and constant disbelief and support of my own basic needs, made me have to internalize, until I couldn't talk "normally" in the minds of others. The growth I've had is to the help of people outside of my "regular" social commitments. Organizations like P.E.A.C.E., LEC Council, INTERCOMMUNITY ACTION, M.H.P., and others have helped me to realize that the life, enjoyment, and mental structure I need and wanted has to be a constant and intentional action of all parts of me.

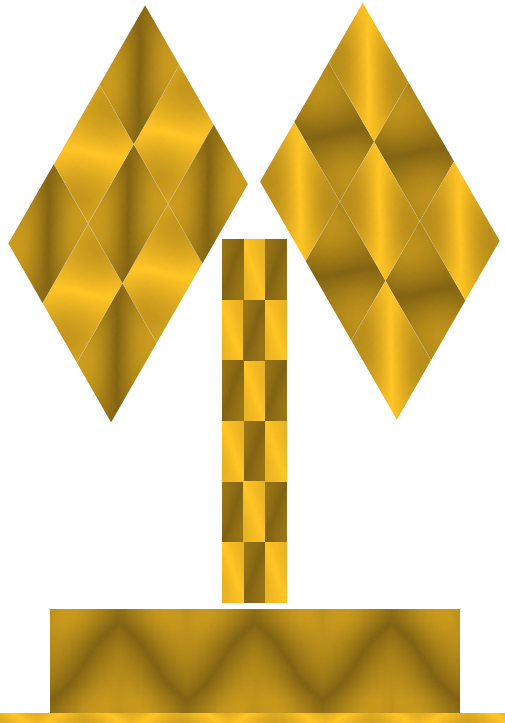
I have been to many clinics and hospitals in the Philadelphia area. I am constantly fighting with racing thoughts, anxiety, and depression. I have coped with my diagnoses and conditions. Music, writing, and art are the three main forms of expression I use to help me with my "mental details". There are many experiences that help me reflect on how far I came throughout the growing of my mental details (the first hospital visit, and the first suicide attempts, along with the drug abuse.)

[During] my first experience with mental health services, I was 14 years old. I had been going through life challenges, from family, friends and school. I was smoking and drinking, and experiencing

suicidal tendencies. I attempted suicide over four times in my life. I was 302d [involuntary commitment] by my mother then, because I attempted to strangle myself, and was self-medicated with cannabis, opioids and alcohol. I was sent to Belmont Behavioral Health, and stayed there for a month. During my times at the mental clinic I have been given multiple medications for different perceived mental disorders.

The medication had side effects, such as loss of appetite, which is also a reason for more medication, and sign[s] of depression, which is what I was diagnosed with first. Then as I got older and experienced more side effects from the medications, it seemed that the more I took medications the more I had relapsed mental episodes. I decided to try more natural ways of coping with my "Life Appendages". Breath exercises and mindful practices worked the best for me. They continue to keep my mind off of negativity and subconscious beliefs of suicide, depression and anxiety, and to focus on the positive in my mind and life.

With the help of the previously mentioned organizations, I have become stable mentally and physically, and hope to continue my journey of mental strength.



Anti-Psychotic Medication

Why We Disengage

- *"They made me feel like I was just a passive object to be medicated and there was really nothing else about me he was interested in."*
- *"Medications not taking away experiences, but the pressure being on trying more and more meds rather than learning to manage myself."*
- *"It always felt like such an unpleasant thing and I just kept dreaming about the time when I just wouldn't have to go to those appointments anymore."*

When Raising Concerns or Discussing Discontinuation

- *"Deep shaming around medication 'non-compliance'."*
- *"Consistently told I just 'lacked insight' into my experience and why I needed meds."*
- *"Psychiatrist said, 'Well, if that's your choice, we'll go with it and just wait and see' and then absolutely no support was offered beyond a tapering of formula."*

How to Improve Communication

- *"Express some actual interest in what the individual is experiencing rather than questions that just seem designed to determine whether medication changes should be made—this comes off as very dehumanizing."*
- *"Don't justify dismissing my concerns by telling me I don't understand what is happening due to psychosis."*
- *"Encouragement of self-care and stressing the importance of wellness strategies if discontinuation is needed."*

Things We Wish Prescribers Knew

- *"It's a huge risk and there are not just pros, but cons that can be life-changing."*
- *"Medications can cause ongoing sedation and mental cloudiness that pretty profoundly impact quality of life and ability to engage in activities like work and school."*
- *"Some individuals may dismiss certain medications and try other forms of treatment based on preference or lifestyle choices."*
- *"Some side effects never go away. I don't want all aspects of my experiences to be taken away."*

LEIT Member Testimonies

"The Lived Experience Collective has been a really unique group, bringing together various voices of lived experience that have helped one another relate and connect. Dealing with mental health challenges can be really difficult. Often, it can be hard to find people who understand what it's like to have the depth of emotions or internal experiences. I'm grateful that the Lived Experience Collective has a group of people who do.

It's been a pleasure being able to help out and facilitate, while also getting an opportunity to listen and connect to others across Maryland and Pennsylvania that I would've never met otherwise."

— Sean "Scoe Romero" Driscoll

"When I first heard that the Lived Experience Collective was being formed, I knew it was something I wanted to take part in. It was clear from the beginning how big of an opportunity this would be. I'd get to be a part of elevating the voices of those who matter most, the very people impacted by coordinated specialty care.

As a peer support specialist, I felt called to this. My work centered around supporting advocacy in my participants. What better way to help improve these systems than to support others getting involved in the research that would bring about positive change?

I am delighted to watch the members put so much effort into every consultation the group does. Beyond this main responsibility of the Collective, it's amazing to participate in various passion projects. The group expressed from the beginning the dream to have a strong impact that will support those currently in such programs and the larger community.

Every month, when I meet with this group, I get to check in and see how everyone's doing. The seasons pass and life continues, yet everyone keeps showing up because we care. No one should feel alone on this journey. We'll practice mindfulness as the topics are often heavy stuff, so this is a moment to center ourselves. Then it's time to get to work.

The future brings many more opportunities. I'm grateful for the part I've gotten to play."

— Jessica Engel

Empowerment

In what ways have your experiences shaped or reshaped your sense of self, identity, or purpose?

"I would say that sharing my story has shifted my perspective from being quiet and secluded to being confident and outgoing."

"I have learned that I... have the potential to thrive day-to-day rather than suffering in silence and conforming to the stigma (being authentic vs. masking all the time.)"

"It was the worst and darkest most challenging moments of my life, which became the best thing that ever happened to me. It helped give me my purpose at a young age. While many people struggle to find it, I always knew from 17 years old onward that I wanted to help others by relating and sharing my story. By 20, I had my first mental health job. I am doing advocacy work and speaking a lot. It's personal for me and I hope to use my personality and confidence to help be an example of not only what recovery could look like, but what triumph and empowerment looks like."

"Tremendously. I don't know who I would be without these experiences. I experience most things on an ongoing basis and have tried to learn to navigate different thoughts and experiences coming up as well as how to reality check."

"My experiences have reshaped my perception about what mentally ill people are capable of."



"I have treated myself with more self-care because of how I perceive myself from my strengths rather than my deficits and limitations."

"I have been able to advocate for not only my own rights and needs, but also on behalf of the wider community. (Community-centered focus.)"

"It has made me very aware of my emotions, needs, and the importance of taking care of myself. I've done a ton of work on myself over many years and I feel grateful for that."

"I do often struggle with my identity in different spaces (am I a peer, a mad person, a student, a person working, etc.) I feel that very often I switch my language and often do not use my preferred descriptions in different spaces in an attempt to fit in there. I have had lots of changes in this over time as well, going through really identifying with my diagnosis then fully rejecting it, and now feeling somewhere in-between. I wish there was more room for beauty, meaning, complexity, and positivity around psychosis."

"I have realized how I was internalizing the societal stigma rather than [being] my own best self-advocate."

"Our group is resilient and kind. We are not only survivors, but advocates in our own way... it's very apparent that people here are strong and dedicated to helping make the healthcare system better."

—LEC Member

Lived Experience Collective

To get in touch with the Lived Experience Collective email LECollective@pitt.edu

https://www.medschool.umaryland.edu/clhs/client-and-family-resources/client--family-advisory-councils/

University of Pittsburgh
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Connection Learning Healthcare System