

POLICY BRIEF

Women-Led, DisAbility-Centered Mental Healthcare Reform in Erie County, NY

By Jessica Lowell Mason

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"I think in general, our mental health system has become a last refuge for people who don't know where else to reach out. For some it provides supportive relationships, connection, and tools. For some it can at least help pave the way getting a disability claim. For many it is a source of immense suffering and trauma, unnecessarily, and we don't talk about this nearly enough. For many it is a source of disconnection and makes crisis even worse, and for a handful it becomes a life sentence, or a death sentence. It is hard to say where the balance lies without thinking about the world of alternatives that could exist in place of this system."

- A local resident with lived experience in the mental health system in Erie County

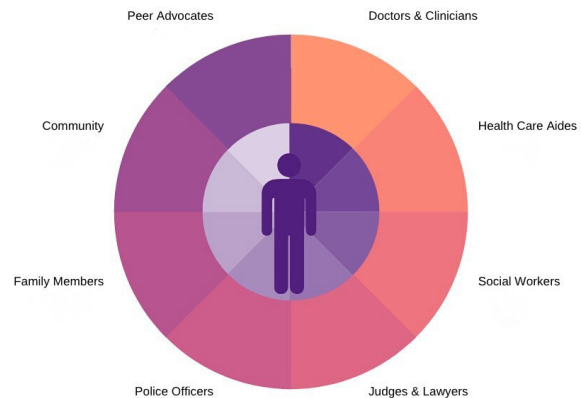
A Crisis in Care in Erie County, NY

Nearly one in five adults is reported to experience a mental illness every year in the United States, but mental health care is sought by less than 40% of those reportedly affected. Erie County is no exception to this national trend, which has led to a push for more services, planning, and community organizing within the county. While efforts to combat stigma and mental illness have increased, our county's citizens are not seeking the care that our system aims to offer. Efforts to recognize underlying issues and additional factors that complicate treatment access and experiences, and that might provide insight into why fewer than half of adults with mental health issues choose not to seek care in Erie County, need to be addressed.

The voices of women with lived mental healthcare experiences in Erie County are a needed part of the county's efforts to intervene upon this crisis, and theirs are perhaps the voices most needed to mend a dysfunctional system. *The mental health crisis is a crisis, not just in health but, in care.*

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Placing Women with Lived Experience at the Center of Our System



Even if all other influences in mental healthcare are equal, a system without a person at its center is without a purpose. The above diagram demonstrates that a system that recognizes an individual as its center - and allows care to be directed by that person- will be more purposeful, stronger, and better equipped to provide self-directed trustworthy care.

What Keeps the Erie County Community from Seeking Care?

- Lack of access to affordable, empowering, person-centered and -directed care
- Lack of avenues for participation that are caused or exacerbated by:
 - Dysfunctions within the care system
 - Poor quality of care conditions
 - Breakdowns in communication between providers and community members
 - Absence of avenues for people diagnosed with mental illnesses to have a direct voice in county government

"The problem is not that we're voiceless; it's that we're not heard."
Viet Thanh Nguyen

Feedback from Surveyed Women with lived MHC experience in Erie County:

"CPEP and inpatient conditions are the most horrifying – dangerous, traumatic, and unhygienic. In my mind these are all punitive spaces, not therapeutic spaces, designed to detain individuals who disrupt the public order and to deter individuals who might seek help elsewhere."
- EC Survey Respondent

"I am generally afraid of any services that bring about police involvement (Crisis Services, etc.), as that can escalate an already difficult situation and lead to unnecessary problems."
- EC Survey Respondent

About this Study

The primary data for this project comes from **seven interviews and surveys** that were conducted with area residents and professionals with experience with the mental healthcare system in Erie County.
- Four surveys on care were completed by women with lived MHC experience in EC. They remain anonymous.
- Two surveys were filled out by (a) a local MH clinician in Erie County and (b) Frank Cammarata, Exec. Director of the Erie County Office for People with Disabilities
- A four-hour interview was conducted with Max Donatelli, Founding Chair of the Anti-Stigma Coalition in Erie County and a member of the EC Community Services Board for Mental Hygiene.

"We are as silenced when we appear in the margins as we are when we fail to appear at all."

- Kimberle Williams Crenshaw

Terms & Acronyms:

- NAMI - National Alliance on Mental Illness
- EC - Erie County
- MHC - Mental Health Care
- CPEP - Comprehensive Psychiatric Emergency Program
- Anti-Stigma Coalition - A campaign to decrease the stigma attached to mental illness in Erie County

Problems in Care Identified by Women with Lived Erie County Mental Healthcare Experience

- Services that are predominated by large healthcare organizations or hospital systems that reduce choice and push out smaller contenders (such as peer organizations)
- Over-emphasis on medically oriented interventions and their promotion (such as through the Anti-Stigma coalition)
- Few choices in crisis (or underutilized choices, such as respite), and an over-reliance on police and emergency rooms in crisis
- Traumatic inpatient conditions at local hospitals combined with not enough access to legal protection and patient advocacy
- Little support for families, or support predominated by a very conservative, medically-focused NAMI chapter
- Lack of information about available services, how to navigate the system, where to get an advocate, and rights.
- Not enough resources to support people with benefits, finances, getting back to work (and generally not enough focus on helping people build the lives they want)
- Too much overlap with the criminal justice system and not enough diversion

Interpreting the Feedback

The four women with lived experience in the Erie County mental health system who answered questions anonymously for this project all reported feeling fear toward aspects of our mental health system.

Fear and care cannot productively co-exist. Fear of our mental health system, especially for women, is a common experience shared by many who have had direct or near experiences with institutionalization. Fear is a factor that we need to talk about and address - recognizing that, for women, fear of the MH system is not about stigma; it is about collective trauma.

Women with psychiatric lived experiences should lead efforts to improve the system because we cannot change stigma without addressing the structures and practices that are causing women to fear mental healthcare.

Did you know?

The Office for People with Disabilities was created when advocates reached out to county officials and requested a voice in county government. [Since then] it has been under the umbrella of Department of Health, Mental Health, and Personnel.
- Frank Cammarata
Executive Director of the Erie County Office for People with Disabilities

Building Bridges between Services and the Community: Women with Lived Experience as Care Leaders

This policy brief proposes interventions that begin with relying on the wisdom of and believing women with lived experience. It is a call for the county to seek out the help of women with lived experience to be involved with mental health policy-making in Erie County, as well as to be included in meaningful ways in conversations and held in positions of equality with government and private stakeholders in the system's efforts to improve care.

I think we have to listen to consumers/patients/their advocates with an open mind and compassionate heart. From my perspective, people feel a higher level of life satisfaction if they are empowered, feel safe, and have opportunities to connect with others.
- A Clinician in Erie County

Nothing about us
WITHOUT US

Women's Leadership and Peer Voices in Mental Health Policy in Erie County

Recommendations:

- **Bring together a diverse group of women with lived psychiatric experiences** to work together with state-funded organizations to improve the **quality of care** and give people with psychiatric experiences in Erie County **a direct voice** in county government.
- Draw from the EC Office for People with Disabilities and from the field of disability studies to **change the status of people experiencing emotional distress**.
- **Develop long-term partnerships** between government organizations, local institutions, and **community members with lived experience in the system** (i.e., consumers, people with psychiatric experiences, survivors, etc.).
- Provide **public forums** for people who are affected by mental health services to provide feedback to institutions of care and to their county government.
- Collect **feedback**, via anonymous public surveys, about mental health institutions and treatment, and **make that feedback available to the public**.
- Develop a **Consumer Voice, Patient Rights, and Institutional Accountability Committee or Forum** made up of both professionals and concerned citizens with lived experience.
- Invite women with lived experience **to have a voice in mental health public policy**, to participate in the **improvement of the mental healthcare system**, and to spearhead restorative and empowering community initiatives.

We want a competent mental health system that is person-centered and allows the person to be in charge of their own treatment. This is not an easy task.
- Max Donatelli
Founding Chair
The Erie County Anti-Stigma Coalition



Community
Resources:



Points to Remember

- Women have a particularly fraught relationship with psychiatric care, historically, and much of the collective trauma that has happened to women through paternalistic control and abuse has gone unacknowledged by the mental health system.
- A lot of what is called stigma is actually institutional discrimination.
- Patient rights violations are part of the mental healthcare crisis in WNY.
- Many women who have been institutionalized have suffered from trauma from the care they received, in addition to whatever kinds of situational and psychological distress they may have been experiencing.
- Women experience trauma when they are not believed and when they are denied choice and denied their bodily, cognitive, and reproductive rights.

References

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- Cammarata, Frank, Executive Director of the Office for People with Disabilities, Erie County. Personal Survey. Nov. 2019.
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