LISTEN TO US:
The Unique Experience of Women with Severe Mental Illness
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EXECUTIVE SUMMARY

Women with severe mental illness face unique experiences and obstacles compared with men with severe mental illness and other women without schizophrenia, bipolar disorder or major depression. Compared with men with severe mental illness, women are more likely to experience a host of negative outcomes due to their severe mental illness, gender and the intersection of the two.\(^1\) Additionally, severe mental illness puts women at higher risk for the negative outcomes that all women are already at heightened risk for, such as sexual assault.\(^2\)

Despite making up more than 3% of the adult population and the vast amount of evidence documenting their disparate experiences, people with schizophrenia and severe bipolar disorder are often left out of consideration in proposed public policy interventions.\(^3\) Women with severe mental illness are even more overlooked.

While there is some research examining how women with severe mental illness are disproportionately impacted, little of it involves listening to their own narratives. To help fill this gap, the Office of Research and Public Affairs conducted focus group interviews to hear directly from women with severe mental illness about the unique experiences, challenges and barriers they face in achieving the lives they want. A graphic recorder was present for the discussions to create a visual representation of the results and capture the conversations in a way that simple data representations and other qualitative methods cannot.

Qualitative analysis of the focus group discussions indicated that women with severe mental illness face compound marginalization because of their gender and mental illness and the stigma, social isolation and disparate treatment that comes with belonging to a marginalized group. There is much to learn by listening to women, and their experiences can help inform solutions that address these disparities.

The following are key findings of this report:

- Women with severe mental illness have long faced institutional biases — the inherent tendency of societal structures to support biased outcomes based on prejudices or stereotypes — because of their gender and diagnoses. Their symptoms are less likely to be taken seriously by clinicians and they are more likely to be misdiagnosed. Yet many women do not see or feel these disparities because gender inequality and the stigma of having severe mental illness are so longstanding and deeply ingrained.

- There are larger barriers to treatment for women with severe mental illnesses than for men with the same disorders, including greater difficulty in accessing inpatient psychiatric beds.

- Social isolation and relationship challenges are very common problems for women with severe mental illness. Motherhood is possible and can be very fulfilling for those women who want children. However, some women feel that the burden of their illness is too much or that they do not want to pass on the genes associated with their mental illness to their children.

- The long road to stability can be empowering for women with severe mental illness. Many of the focus group participants felt inspired to share their stories with the hope of educating and demonstrating to other women that living a fulfilling life is possible.

A woman with severe mental illness is
2x more likely to be imprisoned,
3x more likely to experience sexual assault and
2x more likely to have made a suicide attempt than a man with the same disorder.
INTRODUCTION

More than a half-century of public policy that overlooks or misunderstands severe mental illness has produced many of the major societal problems we see today — people with severe mental illness are living on the streets, behind bars and flooding emergency departments. Women with severe mental illness are at heightened risk for many of these negative outcomes, in part due to the unique experiences they have and the barriers to treatment they face. However, the combined challenges of being a woman and having a severe mental illness are often overlooked by clinicians treating individuals and by policymakers developing policies to try to help.

Research indicates that, compared with men with severe mental illness, women are more likely to be arrested and incarcerated and less likely to be employed or housed. Like women without severe mental illness, women with schizophrenia or bipolar disorder are also more likely to be victimized, including from sexual assault. Although they are less likely to die by suicide, women with severe mental illness exhibit suicidal behaviors at higher rates than men with the same disorders. Mothers with severe mental illness are eight times more likely to be involved with Child Protective Services than mothers without severe mental illness, despite no differences in incidence rates of abuse or neglect.

Mental health providers and researchers often treat people with serious mental illness without regard for their gender, even though gender can have a major impact on mental health experiences and needs. Without purposely acknowledging women’s unique needs, unconscious bias against women and their mental health experiences may arise. Studies suggest that women with serious mental illness experience sexism and gender bias from mental health providers, and many providers are not trained to deal with women’s issues or to understand their unique experiences. In addition, women are commonly pathologized for being more emotional than men, which then influences their treatment experiences and sometimes can lead to misdiagnoses. For example, the onset of illness for 75% of women with bipolar disorder manifests as a depressive episode, compared with 67% of men. Combined with provider bias, this results in women with bipolar disorder being more likely to receive a misdiagnosis of unipolar depression. When misdiagnosed, patients may be prescribed the wrong medications, which can make their illnesses worse.

While women are more likely to seek treatment than men, their symptoms are often taken less seriously by clinicians. For example, in a study of individuals with schizophrenia in an emergency department, despite presenting with more severe symptoms, women were less likely to be hospitalized and, if admitted, stayed for fewer days than men with schizophrenia.
The Office of Research and Public Affairs released a research brief in 2016 titled *10 Ways Women with Serious Mental Illness Are Overrepresented. Underserved*,\textsuperscript{15} which is a literature review of published research presenting the ways in which women with serious mental illnesses disproportionately experience negative outcomes compared with men with the same disorders and women without serious mental illnesses. Missing from this research base is information about how women themselves feel about their illness and how illness impacts their lives and narratives about their unique experiences, which this study aims to provide. The results of the study overwhelmingly suggest that policy solutions to address these negative outcomes for women with severe mental illness must be informed by the women themselves and that listening to them will lead to better outcomes.

**METHODOLOGY**

**Participants**

Participants were recruited through networks of advocates and family members of loved ones with severe mental illness,\textsuperscript{*} including by advertising through email newsletters and Facebook groups. The only participation requirements were for the individual to have a serious mental illness and to identify as a woman.\textsuperscript{†} All diagnoses and participant demographics are from the information participants shared during the focus groups.

Participants included 12 women who had received a diagnosis for a serious mental illness. Their diagnoses included bipolar disorder, schizophrenia, major depressive disorder and schizoaffective disorder. Several participants had one or more of these illnesses co-occurring with each other or with other disorders, such as an anxiety disorder or borderline personality disorder.

The women varied in age significantly: The oldest participant was 83 years old and the youngest was in her early 20s. Participants were not asked to disclose their race but appeared to the focus group moderators to be predominantly white. Since the focus groups were conducted virtually, not every participant chose to disclose her location, but participants noted joining from Hawaii, Ohio, Texas, Georgia and Kansas.

**Focus group procedure**

Two focus group sessions were conducted by the three authors of this research report. Discussions took place virtually over Zoom: One session had four participants and one had seven. Each lasted approximately two hours. Participants received a $50 gift card as compensation for their time. One individual participated by providing written answers to focus group prompts.

\textsuperscript{*} The Treatment Advocacy Center utilizes the phrase severe mental illness to define individuals with schizophrenia and associated psychotic disorders, severe bipolar disorder, and major depression with psychotic features. Serious mental illness, a broader definition that encompasses other forms of mental illnesses that can be seriously impairing to an individual, is also used when appropriate to accurately portray presented research or information.

\textsuperscript{†} This report studied individuals that identify as women and often draws comparisons between women and men. The authors recognize that there are more than two gender identities, but it was beyond the scope of this study to examine related issues.
The focus groups followed a semistructured interview guide with prompts grouped into thematic areas: general experiences, barriers to treatment, relationships, crisis experiences, parenthood, and positive aspects of having serious mental illness. Sample questions included the following:

- What unique barriers to accessing mental health treatment do you experience as a woman with severe mental illness?
- How has your experience with severe mental illness impacted the way you look at your relationships and the future?
- What were your experiences when deciding whether or not to become a parent or have you thought about it for your future?

A graphic recorder was present during each focus group, with a video of his screen visible to participants at all times. Graphic recording is a practice in which an artist visually depicts an event or conversation in real time using pictures, symbols, words and other visual aids to accurately represent the course of the discussion. Participants were able to watch the graphic recorder draw as the focus group discussions took place, and at the end of each session, the graphic recorder presented his artwork, explaining how it represented the conversation. The cover of this report displays part of one graphic recording produced and the report includes segments of it throughout. The Appendix includes all of the graphic recordings from both sessions.

**Data analysis**

The qualitative analysis was based primarily on the grounded theory approach, which advocates developing theories about the data from the ground up instead of imposing preexisting theories onto the text. Zoom audio recordings of the focus groups were transcribed to text using the online software Otter.ai. The qualitative analysis was conducted using Dedoose, a qualitative analysis program, to analyze and code the transcripts.

First, the transcripts were divided by focus group prompt and then independently coded into categories. Then, several different methods derived from experts in qualitative analysis were applied; descriptive and in vivo coding methods were used most frequently. Descriptive coding summarizes the main takeaway from an excerpt and in vivo coding utilizes the language of participants to keep the original meaning of their statements intact. From this initial round of coding, a codebook with over 60 codes was finalized and emergent themes were discussed. Finally, a second round of coding was performed to analyze the themes and identify overarching theories. In this paper, the direct quotes from participants have been lightly edited in some cases for clarity.
FINDINGS

The findings of this study can be categorized in four main thematic areas: treatment access, relationships, stigma and calls to action. These themes were chosen according to the subjects that were coded for most frequently and the topics that resonated the most with the participants’ discussions. These four themes had frequency code counts of 156, 32, 82, and 92, respectively (see Figure 1). The thematic areas also contained subthemes that were coded across all focus group prompts.

All the participants spent time contemplating how their diagnoses had impacted their choices. Some participants saw their illness as a means for bettering themselves and advocating for others, while other participants viewed their illness as having had a net negative impact on their life. One participant said:

I think my life would have been so much different. If I hadn’t had this disorder, I think I could have achieved a lot more. So no, there’s nothing positive about it in my opinion.

Throughout the course of each focus group session, participants brought up comparisons between men and women and how those differences related to their treatment course or worldview. Two codes were used to highlight these phenomena in the transcripts and the codes appeared most often in the barriers to treatment prompt (see Figure 2).

Often, the participants would compare their experiences as women and discuss how gender may have affected their lives but would simultaneously say that they did not believe that their gender negatively impacted their lives. However, comparisons between men and women were brought up repeatedly over the course of the focus groups, indicating that gender differences were impacting the participants’ lives, whether expressly acknowledged or not.

Figure 1. Prompt frequency, by theme

<table>
<thead>
<tr>
<th>Code</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comparisons with men</td>
<td>19</td>
</tr>
<tr>
<td>Societal perception of being a woman with severe mental illness</td>
<td>14</td>
</tr>
</tbody>
</table>

Figure 2. Comparisons with men code frequency
Treatment access

Many women with serious mental illness experience difficulty accessing quality treatment. These sometimes-insurmountable barriers were a common theme among the focus group participants: When discussing the shared experience of being a woman with serious mental illness, participants mentioned subthemes regarding treatment access, experiences with treatment or barriers to treatment 156 times. Participants repeatedly highlighted how their illness journeys had been impacted by their often-negative experiences with the mental health treatment system.

Although there was a specific prompt about treatment barriers, factors and subthemes regarding treatment access arose in every prompt of the discussion. Within the two focus group discussions, participants’ excerpts were coded into 15 subthemes in four categories that had a connection to treatment access. These subthemes were mentioned in the focus group sessions with high frequencies, as seen in Figure 3.

Figure 3. Treatment access subthemes, by focus group
Consequences of nontreatment

Previous research indicates that there are significant consequences associated with women not receiving quality treatment for severe mental illness, including victimization, involvement in the criminal justice system and homelessness, which can then impede treatment access.

Figure 4. Consequences of nontreatment code frequency

<table>
<thead>
<tr>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criminal justice system involvement</td>
<td>16</td>
</tr>
<tr>
<td>Homelessness</td>
<td>4</td>
</tr>
</tbody>
</table>

Focus group participants explained the consequences of nontreatment in their lives and their experiences when they attempted to access treatment. Involvement with the criminal justice system was mentioned 16 times alongside homelessness, which was mentioned four times. Both events impacted the treatment trajectories of participants and altered the way that they viewed their mental illness. Participants indicated that prior to receiving any treatment, most of their experiences with their serious mental illness stemmed from interactions with the criminal justice system. One participant reflected on a personal experience of criminalization when she was once actively experiencing a psychotic episode:

I wish I'd never been taken to jail for one single day. I mean, when I was picked up and incarcerated while homeless, I was acutely psychotic. If I had been having a heart attack ... I would have been taken to a hospital. But my psychosis was ignored or not recognized. And even though I belonged in a treatment center, I was mistakenly taken to jail. And I mean, this happens every day. It is so common.

Interactions with the criminal justice system at times when participants were symptomatic led many to be criminalized during a time when they desperately needed quality treatment instead. Individuals with serious mental illness are often placed in jails and prisons without proper treatment for months at a time, as described by one participant:

I got pulled over and I was totally psychotic. And I ended up in jail for two months. And I really was traumatized by the experience. And I really think that police should direct the mentally ill to treatment and not incarceration.

Another participant explained the difficulty of getting assistance when your mental illness is combined with anosognosia, or the inability to recognize that you have a serious mental illness. She described how, in her home state of Hawaii, incarceration can sometimes be the only option for people with mental illness:

And the only way to truly get help if you are that mentally ill and incapable of knowing you’re mentally ill, the only way to go is jail ... And then you can be transferred over to the state hospital. And that's all they do. And once you’re well and better, they take you back to court and trial you.

Participants’ treatment journeys were often slowed or interrupted by their experiences with the criminal justice system and homelessness. The same participant explained that she had been homeless for almost half of her life, since the age of 14. She wished there had been housing support to assist her when she was experiencing psychosis. One participant indicated that her experience with incarceration still has rippling effects on her ability to heal:
It was really, really traumatic. And I don’t feel it, even though it’s been like, I don’t know, seven years or something. I’m still not over it. I think it’s inhibiting me from moving forward. Because when I try to write about it, it’s so painful to relive it, that I can’t seem to do that.

Participants outlined the basic reality for many women with mental illness: When experiences of homelessness and incarceration intersect with a lack of community social support, women are at a greater risk for victimization and negative health outcomes. These experiences show that women face many barriers to receiving treatment and experience immeasurable impacts from the criminalization of mental illness, including trauma. Many spoke of their desire for improved crisis intervention responses when they are experiencing psychosis rather than responses that force them into the criminal justice system.

**Treatment experiences**

Participants spoke about their experiences seeking and receiving treatment for their mental illness and shed light on topics such as hospitalizations, quality of care and shared decision-making. All participants had received inpatient psychiatric services at least one time in their lives. Participants’ lengths of stays and interactions with the hospital system varied greatly. One participant stated, “I’ve been in the mental hospital over 40 times in the last 10 years.” Another participant explained her experiences with hospitalization over a two-week span, noting that staying in the hospital for two weeks is now uncommon and many hospitals instead opt to “load you up with medication and release you in two days.”

**Figure 5. Treatment experiences code frequency**

<table>
<thead>
<tr>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not being taken seriously</td>
<td>21</td>
</tr>
<tr>
<td>Negative experience seeking treatment</td>
<td>16</td>
</tr>
<tr>
<td>Negative quality of care</td>
<td>15</td>
</tr>
<tr>
<td>Positive quality of care</td>
<td>14</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>11</td>
</tr>
<tr>
<td>Empathetic care/compassionate care</td>
<td>11</td>
</tr>
<tr>
<td>Strong support from psychiatrists</td>
<td>6</td>
</tr>
</tbody>
</table>

One participant from Georgia described her previous attempt to receive care in a hospital:

Georgia will leave you in the hospital for three days in an ER, and you will never see an actual psychiatric bed. You will never see a med change ... You will go home in three days, and you’ll have spent the entire time in an ER room that’s padded.

Several participants described struggling to receive a diagnosis for their symptoms. They attributed it, in part, to misunderstandings from health care professionals based on their gender. Participants pondered if they would have been evaluated differently by medical professionals had they been men:

And I just wonder if psychiatrists and therapists see what they want to see and aren’t hearing all of the details. That women don’t have the same classic symptoms [that] show up in the DSM [Diagnostic and Statistical Manual of Mental Disorders] — that’s been my experience, that it doesn’t look exactly the same and so [that is] why [I’m] not getting the treatment.
Participants felt that they did not fall into a single category compared with the symptomatology of others. One participant described a time when she started doubting herself after attempting to get through to psychiatrists and being confronted with unempathetic care. Some questioned how their illness journeys and diagnoses were affected by their gender:

> Sometimes it seems like psychiatrists don’t understand my symptoms. I’m bipolar with anxiety. And it doesn’t always fit into the classic bipolar manic or depressive episodes. I have a lot of mixed episodes. And it took a long time for that to be heard and understood. And sometimes I wondered if that was because I was a woman — was it because my symptoms didn’t match up exactly?

Medications can affect people differently, and drug side effects are often experienced in a variety of ways due to a number of factors, including gender and sex. In recent years, researchers have called attention to the lack of racial representation in drug trials and how racial differences may affect how a person experiences medication, but there has been less attention paid to gender differences. One participant connected the side effects from her medications to the lack of gender representation in drug trials:

> It took a very long time ... to find medication that worked for me, and I feel like one factor in that was that the trials that are done for medications are primarily done on men. And so the side effects that I would have or the lack of response to a drug or even things like it says there’s no weight gain. Well, I gained 60 pounds, so you tell me ... This was, you know, something going on in my metabolic system. And that seems like a factor for me with being a woman.

Women described issues with other treatments as well — one participant felt slighted in her Transcranial Magnetic Stimulation (TMS) treatments, in part because of her gender:

> As a woman living with a significant mental health condition, at times I have felt like my experiences have not been taken as seriously ... On my last visit, I expressed to the doctor that my biggest goal was to prevent relapse. He asked me about my depression, things like, “Is it just that you feel down sometimes? Do you keep a journal to see how depressed you are?”

She went on to describe her long struggle with serious mental illness, including how she had already done TMS treatments in the same year, been hospitalized three times and been suicidal for long periods. She felt that the doctor minimized her lengthy history, treatment needs and knowledge of mental illness with his questions, treating her as if she did not actually suffer from a serious psychiatric disorder that needed intensive treatment.

Another significant part of the discussion of participants’ experiences with their serious mental illness related to whether they had been listened to or acknowledged in the shared decision-making process of their treatment. Mirroring other research about how women’s health is routinely taken less seriously in the general health care system, like in maternal health care, participants mentioned more than 20 times that they felt they were not taken seriously within the health care system. The need for empathetic care was widely acknowledged among participants and mentioned 11 times. Empathetic crisis care management was regarded by participants as a vital necessity for treating individuals with psychosis:

> When I am in crisis, I need people to listen and try to help me get the best help for me. In the past, sometimes it has felt like providers cared more about checkboxes and liabilities than about my well-being. When someone takes the time to care, that has meant the most.
Participants routinely described their frustrations about not being listened to within the health care system and feeling that their mental illness was often belittled. They had to advocate for themselves and demand the equitable treatment they knew they deserved:

Because you’re not, you’re already not taken seriously, because you have SMI. You’re going to have to push harder, you’re going to have to advocate for yourself, because nobody else is going to do it like you.

Empathetic care and strong support from psychiatrists are two vital subthemes that emerged from the discussions about participants’ experiences with mental illness treatment. Participants called for an increase in education and bias training among health care professionals to expand empathetic care toward individuals with serious mental illness. Analysis of participants’ experiences indicated that empathetic care is essential for dealing with women with mental illness. This care stems, in part, from a deeper understanding of illness journeys and acknowledgment that symptomatology does not always fall neatly into strictly defined categories.

Health care systems

Participants also reflected on their experiences receiving treatment within the U.S. health care system. They highlighted topics such as high costs, geographic barriers to access, a lack of service providers and lack of access because of their serious mental illness. Ability to pay for treatment is a significant factor in an individual’s treatment path and it was mentioned seven times among participants. Most participants indicated they are covered under Medicaid, a federal and state public health insurance program. Several participants mentioned that without insurance coverage, their medications and treatments would be too costly.

Figure 6. Health care systems code frequency

<table>
<thead>
<tr>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of treatment access</td>
<td>9</td>
</tr>
<tr>
<td>Lack of inpatient beds</td>
<td>9</td>
</tr>
<tr>
<td>Cost/insurance coverage/coverage gap</td>
<td>7</td>
</tr>
<tr>
<td>Geographic differences</td>
<td>6</td>
</tr>
<tr>
<td>Psychiatrist shortage</td>
<td>5</td>
</tr>
</tbody>
</table>

The ability to pay affects all individuals with serious mental illness and participants repeatedly mentioned that their pursuit of work comes at the price of losing Medicaid coverage for medications that cost thousands of dollars out of pocket, as outlined by one participant:

My Latuda right now is incredibly expensive, like $2,000 a month or something, and I get extra help from Social Security, but that’s only if I’m under a certain income level. So, I can’t work. If I work, I will lose the extra health [benefits] and I won’t be able to afford the medication ... So, I’m kind of in a dilemma.

Another participant followed up with a similar experience:

My Invega shot costs $3,500 a month, and I pay 50 cents for it. My dad is saying that I’m becoming better, and he sends me jobs to apply for, part-time jobs, and he wants me to get a ticket to work. But I really can’t run the risk of losing the Invega shot because right now, it’s the only thing that’s working.
Alongside the ability to afford medications, individuals with serious mental illness confront geographic variation in the accessibility and quality of treatment. Accessing psychiatric services in more rural areas comes with difficulties, such as physician shortages and lack of beds, which were mentioned five and nine times, respectively. One participant noted the dire need for more trained mental health clinicians in her county:

There are literally three therapists for the entire county. There are two psychiatrists for the entire county of everybody that's on Medicaid. And to do that is just insane.

Even when they had been transferred to psychiatric care, participants indicated that they found a lack of equal bed spaces for women compared with men. Individuals often have to wait for hospital beds for weeks, months and even years at a time, regardless of gender. However, women may experience even longer waits due to rooming requirements. One participant from Texas who has been hospitalized over 40 times in the last 10 years described a common experience trying to get a bed in Texas:

[When] trying to get placements in mental hospitals, I often had to wait a long time because there wasn’t a room for females. They would have more men on the units than women. And it felt like there just wasn’t enough space.

When confronted with the lack of providers and lack of hospital beds, women with serious mental illness who seek treatment often feel discouraged and ignored by the health care system. Participants with routine physicians described their gratitude for their psychiatrists, as they understand the extreme shortage of people entering the profession:

I am very lucky at this point to have a psychiatrist who really has gone above and beyond to help me. I see him through an FQHC [Federally Qualified Health Center] and have been able to see him even during times when I do not have insurance.

While it is impossible to verify the true intentions of the health care professionals and community members described by participants, the women had the perception of potential bias based on gender in some areas. These perceptions can impact treatment experiences and adherence, potentially impacting the overall recovery process.

Participants’ experiences with treatment exhibit how the U.S. health care system is not equipped to handle the dire needs of individuals with serious mental illness. Factors such as high costs, gaps in insurance coverage, insufficient quantity of care providers and lack of infrastructure and services paint a bleak picture of how participants’ lives are made more difficult when trying to access treatment. These issues stem from a continued lack of health care equity, treatment prioritization and accessible treatment options for individuals with serious mental illness, especially women.

Long road to stability

Participants’ statements illustrated how reaching stability through treatment is a long road for those with severe mental illness. Compounding factors such as consequences of nontreatment, negative treatment experiences, suicidal thoughts and inadequate health care infrastructure make the lives of individuals with serious mental illness more difficult and impede their efforts to reach stability and/or recovery.
Individuals with serious mental illness are at an increased risk of suicide.\textsuperscript{22} They are at an elevated risk of suicidal ideation and more likely to act on their suicidal feelings.\textsuperscript{23} Suicide was mentioned nine times in the focus group discussions and several participants mentioned past occasions when they had attempted suicide. Participants also expressed difficulties in recovery due to inadequate health care services after attempting to take their own lives:

I tried to overdose and someone found me and I was taken into hospital. And I was in the emergency room, and I came to ... and I started struggling because I was like, freaking out. And the nurse said to me, “Lay still, you did this yourself.” So, the level of unempathetic care that we're getting ... and this was a suicide attempt that I made after I sought help.

It is also important to account for basic needs and social supports when analyzing the well-being of individuals with severe mental illness. One participant described how health is all-encompassing, beyond just mental well-being:

Having a house, having food, having utilities is a part of mental health wellness — when you have a serious mental illness and you cannot provide a roof over your head, you cannot provide food in your belly, you cannot provide heating or cooling — it gets to 108 degrees here in the summer.

When treatment systems failed and discouraged participants, they had to look inward to find strength and to stand up for their well-being. One participant explained her initial experience with psychiatric care and how her ability to thrive was quickly diminished:

So, when I was diagnosed with schizophrenia in 2007, within about 36 hours, the psychiatrist decided I was permanently, totally disabled — [that I could] never [go] back to school, never work again, never live independently. And he was totally wrong.

Participants mentioned the importance of advocating for yourself in individualized treatment plans and with psychiatrists. One participant reflected on her progression and road to stability after routine medication, a committed plan and a strong support system:

So, I guess I feel like my life had a happy ending. And I’m tremendously grateful for Clozapine, which worked best for me and my recovery ... For me, things have turned out well, but yeah, I mean, it is tempting to look back at your life and just wonder, what would it have been without mental illness? Would I have higher education right now, would I be married now, would I have children now? And I'm happy and I can’t complain.

A common thread that ran through all statements and experiences was the difficulty of accessing equitable treatment and receiving care that was tailored to specific needs, which ultimately delayed treatment. Some of the participants expressed a desire to feel valued and supported within their care plans and when asking for help regarding their health. Compounding barriers to treatment access, fragmented care and the lack of equitable services made achieving stability a long and unpredictable road for many participants.
Relationships

How we connect and bond to each other as people is an essential aspect of our lives. We form many different types of relationships with others over the course of our lifetime, including with our caregivers, friends, romantic partners and children. Without the ability to form meaningful relationships with others, individuals are more likely to have physical and mental health issues and report having less fulfilling lives.24 Social isolation and loneliness are very common in individuals with severe mental illness.25 Previous research suggests that combatting loneliness in people with severe mental illness is important for stability.26 This may be especially true for women with severe mental illness who have been shown to value relationships as a more important aspect of their personal lives.27

Figure 8. Relationship code frequency

<table>
<thead>
<tr>
<th>Code</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative relationship experiences</td>
<td>17</td>
</tr>
<tr>
<td>Positive relationship experiences</td>
<td>15</td>
</tr>
</tbody>
</table>

In the focus groups, participants acknowledged their many relationships and how these relationships are affected by their mental illness diagnoses. They were thankful for the “villages” that supported them throughout their lives and new relationships that emerged because of their illness. One participant attributed the shifting of her relationships to her mental illness diagnosis:

My illness has radically changed the dynamics of my relationship, both within my family and with friends and with partners, and radically changed the course of my life.

Figure 9. Relationship code percentage

- Positive relationship experiences: 47%
- Negative relationship experiences: 53%

Family support or strain

Participants had varied experiences with familial relationships. Some individuals described their relationships as strained or difficult to manage, while others experienced the utmost support from their family members. Some individuals also spoke of rekindling relationships with family members after years of disconnection.

Many participants explained the power of having a strong family support system to help deal with serious mental illness and some credited their recoveries and triumphs to their strong familial support. Some participants expressed that having family members vouch for their treatment, success and growth made a difference in the way they perceived their illness and ability to thrive:

I have a really strong family, that helps me get through things right now. They've always been very supportive and helping to me. And then I just have a strong family bond with my family members ... So, it's just really helpful that I have that.
Another participant expressed her continued thankfulness for her parents, as they refused to give up on her illness journey after her diagnosis:

My parents absolutely would not give up on my recovery. Even when I was at my sickest point, they're like, you're going to get your life back. This is not the end.

Participants discussed times when their family relationships faced immense pressure and strain due to many factors linked to mental illness, such as instability, stigma about their diagnoses, shame, and symptom severity, as well as the high burden of caregiving for medication management and other treatments. One participant diagnosed with borderline personality disorder and major depressive disorder explained the irreversible strain on her personal relationships with her children and family members that she attributed partly to her mental illness:

I pushed myself away from them because I wanted to protect them. I didn't want them to have a mom that was crying and had these outbursts and was feeling suicidal; I didn’t want them to witness that, and now they're adults ... I have no family. My parents, I don’t speak to my parents. I don’t have literally a family member that speaks to me. All broken relationships.

Participants also stated that they experienced rekindled relationships with family members that made a positive difference in their lives. They recounted previous strained familial relationships due to disagreements about the need for medications and difficulties and misunderstandings often related to their serious mental illness symptoms. Despite at one time experiencing strain and hostility from her family, one participant expressed that now her family relationships are the most important thing in her life and she has the chance to help babysit her grandchildren:

For a while, my family rejected me because they said there was too much drama. You know, my sister made fun of me. And it was terrible. But after I got on a good antipsychotic and was able to act more normally and not produce drama, I guess, they've come back to me. And that has made such a big difference in my life. And my children, who resented me because I left them when they were young, they are very much in my life now. And I babysit for them because they have children. And that has really made such a big difference — and realizing that I needed to be on an antipsychotic forever. That's been the major difference.

While some participants spoke of how their serious mental illness has negatively impacted their relationships with their family, other participants spoke about family with great pride and cited familial support as a driving factor in recovery. Whether it be helping with day-to-day tasks, advocating for participants’ treatment plans or providing emotional support, family members and caregivers can play an important role in the lives of individuals with serious mental illness.
Romantic relationships

Participants also explained their previous experiences with romantic relationships when living with severe mental illness. Several participants mentioned having gone through a divorce, some participants were using online dating applications and one participant was a widow. Although not every participant mentioned direct experiences with a romantic relationship and dating, all provided their thoughts on the topic.

They shared stories of both successful and unsuccessful relationships and how that intersected with their mental illness diagnoses. One participant in her 80s expressed gratitude for her husband who had unwavering loyalty, especially when she experienced instability with her mental illness:

I was lucky, in many ways, because I did get married to a very sympathetic man who stood by me through all of this, including my hospitalization.

Participants indicated that their day-to-day routines and treatment plans occupy the majority of their mental capacity, which leaves little room for romantic relationships. Few participants attempted to engage in romantic relationships and those who did noted both unsuccessful and successful experiences. Some stated they were surprised when a romantic relationship was successful and they were able to form a connection with someone else. One participant explained her excitement about a positive dating relationship:

And we've been together for over two years and things have been going really well. Which was a big surprise to me. I didn’t think that would ever happen even though I was looking. I hoped for it, but I didn’t know if it would happen because of my illness. Because my life was so dictated by what the bipolar was going to do. It was so unpredictable.

When looking back on previous romantic experiences that ended, two participants indicated that their partners were unable to stand by them through their symptoms or treatment needs. Participants never outwardly stated that their partners were their caregivers, but they did explain that their relationships became divided due to the responsibilities that accompany providing care and support. Multiple participants expressed that the main pillars of their relationships, such as communication, support and planning for the future, fell to the wayside when their mental illness began to interfere with their lives. One participant attributed the dissolution of her marriage to her unstable mental state and need for treatment:

But we’re still friends, but that marriage was very rocky, and he could not handle the psychosis, because I was in and out of the hospital with psychosis. And he was like, “I'm just done. I can’t do this anymore.”

Another participant explained that her mental illness led her to personally take the future of her relationship into her own hands. She was unable to envision her happiness within her marriage:

Mostly because of my illness, I divorced my husband after 16 years. It wasn’t the future that I could envision or wasn’t the present that I could live with, it was just we didn’t have a strong relationship, and he couldn’t support me. And with my illness, what all that would mean for the rest of my life.

Participants reflected on previous experiences within romantic relationships that gave insight into some priorities, goals and aspirations for moving forward with their mental illness. One common thread was the necessity of consistently advocating for your own treatment. Whether they were currently in a
relationship or had never experienced one, they knew what choices worked best for their personal lifestyles and health.

**Friendships**

Participants also reflected on the intersection of their friendships and their severe mental illness. Multiple participants spoke about how they lost friends after disclosing their mental illness, likely due, in part, to the stigma surrounding severe mental illness. Participants expressed their discontent about losing friends who knew them before their illness, as they felt their friends did not give them a chance to explain their situation. One participant reflected on the dichotomy of her friendships throughout her life:

> People who knew me when I was severely mentally ill could not believe I’ve ever achieved recovery. And people who know me now, fully recovered, can’t imagine me sick … People who knew me many years ago, when I was psychotic, a lot of them don’t want to have anything to do with me anymore, or really are keeping me at arm’s length. And then people I have in my life … see me as normal and [think that] I’m an ordinary person, I’m a successful person.

When talking about friendships, one participant acknowledged her worries that her mental illness would push people away from her if she said something considered abnormal:

> I think relationships are a challenge. Because there’s always this fear in me that I’m going to say something that is going to be “wrong.” Like I grew up, like, I’m all black-or-white thinking; it’s really hard for me to have grace with myself and to say, okay, so I messed up with what I said to that person.

Although every participant mentioned the topic of losing friends due to their mental illness, many were not ashamed and hoped to continue to foster friendships that supported them with their illness. Participants valued friends who took time to understand and see beyond their serious mental illness.

**Motherhood**

Navigating motherhood as an individual with serious mental illness has its own unique set of challenges. Research on mothers with severe mental illness involved in the criminal justice system found that women centered their lives and recoveries around their identity as mothers, despite their reports that their mental illness made motherhood an impossible task. Many also suggested their main goal in motherhood was to make the lives of their children better than their own, breaking familial cycles of pathology, trauma and disadvantage.
The decision to have children and the responsibility that comes with becoming a mother is often a difficult one for women, but especially for those with severe mental illness. Genetics do play some role in the cause of schizophrenia, but a much more modest role than previously thought. However, even a modest chance of passing on their severe mental illness may cause some women to decide not to have children. Additionally, the symptoms of many disorders and the level of impairment that may come with severe mental illness can make taking care of a child extremely challenging and stressful, making some women hesitant to become mothers. Other research suggests that the increased risk of perinatal mental health issues in women with severe mental illness contributes to individuals’ hesitancy to have children, especially because there is some risk associated with taking psychotropic medications while pregnant.

In the focus group sessions, participants reflected on their decisions about whether to have children and their experiences with motherhood. Most participants seemed to believe they had made the right decisions, whether they had decided to have children or not. One participant described her experience as a mother with mental illness:

*Parenting and being mentally ill can be a questionable thing but can definitely be done. It’s absolutely possible but it’s a lot of battling within yourself. So having a good support system definitely helps.*

Three participants in the focus group were mothers, while others indicated that they might later decide to have children. The mothers explained that their children brought a sense of fulfillment and added value to their lives. Having children gave these women an incentive to remain healthy so they could provide their children the best care and feel a sense of empowerment about setting a good example for them. One participant explained her mindset when she discovered she was pregnant long after having lost contact with her two adult children:

*Well, God blessed me three years ago with one more chance to be a mother, which was all my heart ever desired. I feel like I’ve been chasing my kids my whole life. And I knew I had to go all in.*

This same participant explained how her child motivates her to remain on a steady treatment path. She wants to do her best, not only for herself, but for her child as well:

*It really makes me try to work as hard as I can on myself just so that her upbringing isn’t, you know, just doesn’t have all my outbursts and my lack of coping skills and everything else ... I’m more determined than ever to take care of her and keep going through this. I mean, having her for two years all on my own is like a big thing ... it is really hard. It’s always a constant battle within myself if I can do it or not. And if she gets what she deserves.*

These feelings of determination and resilience were mirrored by another participant who expressed her gratefulness for her role as a parent:

*He’s my whole life. I don’t know what I would do without him. He’s definitely my drive and push. I don’t regret having him or anything. I know I’m a single parent. He knows I love him and stuff. And he definitely helps me out a lot. He definitely helps me push through.*

Of those who decided not to have children, some said that they did not want to pass on the genes associated with their severe mental illness, while others indicated that they did not think they could take care of a child. Participants often reflected on their decisions in a selfless manner, as they directly accounted for the potential health of a future child. Some women talked about how they did not want their kids to have to deal with their own mental illness symptoms. They did feel confident in their final
decisions on motherhood, despite the continued sadness of not having a child. One participant reflected on her logic for not having children and the attached feelings of remorse:

> It absolutely breaks my heart that I don't have kids, it really, really does. But I just try and remind myself that, you know, I don’t have another little person running around, having to suffer like I did when I grew up. It is the only thing I have to hold on to, but it is very, very difficult the decision about whether or not to have children. And I think it's an unfair one in some ways.

Participants shared their opinions about having children despite societal perceptions that they are unfit or too ill to become mothers. They expressed their frustration with that opinion and how their voices are sometimes ignored in conversations about parenthood. Participants explained that they want to be the decision-makers in their lives, including in the choice to become a mother. One participant with a 4-year-old child expressed her viewpoint as a mother with mental illness:

> People think that we shouldn’t have kids. But I think it's okay that we do still, it's just going to be a lot harder than [for] people that don’t have mental illness. But there’s people that say that we can’t. I feel like everybody has their own opinion.

Regardless of their decisions to be mothers or not, participants conveyed the importance of the ability to make decisions regarding their family lives.

**Relationship with self**

Participants frequently commented on self-worth and self-love, regardless of how others viewed or treated them. Participants explained how dealing with mental illness shifted their outlooks on life and their futures. Through reflection and thoughtfulness, participants shared that the relationships they have with themselves is one of the most important relationships in their lives. They are the ones who keep themselves motivated every day and refuse to give up on treatment and progress. One participant summarized the importance of positive self-talk:

> And what it really boils down to is self-talk, positive self-talk and the way we view ourselves, and having a mental diagnosis is so incredibly difficult to look at yourself and love yourself ... How you want to be loved is how you need to love yourself. And when you love yourself to that degree anything is possible ... And I’m learning how to love myself because it’s the one thing that I’ve never done ... And I find the best way to love myself is reaching out to try and help other people.

One participant explained how her relationship with herself amid her mental illness has evolved over time despite some bumps along the way:

> It took me a long time because I was hating myself ... And just now that I’ve accepted, now I could devise a plan and a road map of what I got to do when stuff hits the fan. And it's really, really helped a lot.

All participants expressed gratefulness for the multitude of relationships in their lives, including with family, friends, romantic partners, children, and with themselves. They understand that in light of their mental illness, they have to empower themselves. Even in the most difficult times, participants need to believe in themselves to continue to advocate for their own well-being.
Stigma

There is a degree of social stigma associated with having severe mental illness, meaning that some individuals hold negative beliefs about people with severe mental illness, sometimes resulting in discriminatory behavior. Stigma emerges in two primary ways: internal and external. External stigma is the most obvious and comes from negative judgments of those with mental illness by others, like family, friends, strangers or institutions. Internal stigma or self-stigmatization is negative judgment turned inward by the person with mental illness, which impacts how they see themselves.

Previous research suggests the internalized stigma of having serious mental illness is experienced differently by men and women. In a study examining the differences between men and women’s experiences of psychosis, men felt they were often perceived by others as dangerous while women more often felt that others treated them like children or minimized their experiences, and they often experienced paternalism in relationships.

Though none of the prompts in the focus group sessions directly mentioned stigma, it was a recurring theme throughout responses to all prompts, appearing most frequently in the relationships and outlook discussions. Participants noted the impact of stigma on all aspects of their lives: relationships with friends, family and romantic partners; jobs and school; and internal thought processes.

External stigma

Most direct acknowledgments of stigma referred to perceived stigma from external sources. Sometimes, external stigma can result in scenarios of actual discrimination based on a person’s serious mental illness. One participant, a current college student living in the United States who grew up in China, recalled how her high school attempted to bar her from returning to school following her psychiatric hospitalization episode. The school argued that it was not equipped to handle her mental health needs, though she was able to have doctors vouch for her safety to return to school. She was eventually able to get the decision reversed by appealing to the government, but it is clear that this pushback from her school had a major impact on how she viewed herself and her illness. The discriminatory actions of the school likely resulted from negative attitudes and misconceptions that administrators held about mental illness and the safety of individuals who have had a psychiatric hospitalization.

Since stigma surrounding mental illness can arise from the viewpoints of others, it is logical that references to stigma arose most often in the relationships portion of the discussion. Every participant referred to stigma directly or indirectly when describing how their severe mental illness impacts their relationships, more often indicating that stigma had a negative impact on one or more of their relationships.

Participants reported losing friends once their severe mental illness diagnoses were discovered. This also happened to those who were currently dating or have tried dating in the past. In describing one early dating experience, a participant said, “Because they found out I was bipolar, they didn’t want anything to do with me, because of stigma.” Several participants applied meaning to their loss of relationships by noting that this stigma stemmed from their friends’ lack of understanding of severe mental illness and its symptoms.
Several respondents referenced the idea of “coming out of the closet” or being “outed” to describe their struggle in deciding if, when and how to tell people about their serious mental illness. One participant described this phenomenon in the context of her dating life:

And now that I’ve started dating again, you always run into this problem when you tell somebody that you’re bipolar. I mean to me, it’s basically a physical brain disorder, something physically wrong with your brain. So, it’s like we sort of are, like, diabetic, right? We take medications to balance ourselves out, like you take insulin. You know, if I was dating somebody, when at what point it’d be incumbent on me to tell them I was diabetic, I sort of think of it that same way. So, I try not to tell them early on, so they get to know me.

Any participant who referenced their dating life made a similar claim about not wanting to share their mental health diagnosis too early, but not wanting to hide it either. This appeared to apply to some friendships as well, especially for one participant in an assisted living facility who feared that she would be stigmatized by others if they knew her diagnosis.

Internal stigma

Many participants described scenarios that indicated the presence of internal stigma or self-stigmatization, but without directly acknowledging it. This internal stigma appeared in the same contexts as external stigma: in how participants approached relationships, careers and treatment. One participant described her views on dating, connecting them to her self-image:

I don’t feel like I can be in a romantic relationship with everything that I have. I don’t think anyone would want me and I don’t really live a productive life. Like, I’m not fully employed and I don’t have my own house or drive a nice car.

She tied her mental illness, and what she views as its impact on other aspects of her life, to why she thinks she would not be accepted by a romantic partner. Despite no indication of past rejection, she assumed a negative outcome if she were to attempt dating because of her negative view of herself and her serious mental illness. This theme arose for several of the participants in various aspects of their lives, with one participant aptly summarizing the sentiment by saying, “Having a mental diagnosis [makes it] so incredibly difficult to look at yourself and love yourself.”

Gender stereotypes

One participant related mental illness stigma to the broader stigma that is associated with different genders. For the most part, she saw no differences in the effects of stigma on women and men, but she did note that she thinks women are more likely to reach out for help with their mental illness compared with men:

But as women I think that we reach out for help and for treatment, perhaps more so than men do. Men typically don’t reach out for help.

Another participant built on this sentiment, explaining:

I think men ... they’re supposed to be strong and not show their emotions a lot of the time or they [have] been taught that way or [to] work hard or be the provider of the family.

This internal stigma is likely present in varying degrees for anyone living with serious mental illness, but this participant assumed that the additional pressures on men to not show weakness may make them particularly susceptible to deciding not seek treatment.
One woman raised in a conservative, religious community noted the difficulty she had fitting into the community’s expectations, especially after receiving her mental illness diagnosis:

People try to a lot of times [to] control women because women are supposed to be prim and proper and have this certain path in life. And I definitely didn’t fit the mold ... especially in certain groups; like Christian, certain churches and stuff, have this idea that women have to fit this certain mold, and then you can’t talk about mental illness at all, because it’s a sin, and especially as a woman in our society, you know, it’s you’ve gotta be, got to look good. And you’ve gotta act good. And you can’t have anger, for sure.

Participants alluded to a type of double standard in which women were expected to not show certain emotions but simultaneously had many of their serious mental illness symptoms mischaracterized as emotional responses.

Demystifying stigma

While many of the women noted negative experiences with stigma, there were also stories of participants overcoming stigma and finding ways to reduce it in their lives. As several participants noted, much of the stigma they encountered came from a lack of knowledge about severe mental illness from others. When discussing the focus group, one participant noted:

To me, sharing like this gives me hope to hear other people and different perspectives, and different people’s experiences ... And I think what’s so important is to not be afraid not to share everything with the first person you meet at the coffee shop or whatever.

Another woman used her platform writing a blog for her local newspaper to speak about mental illness, educate her community and publicize the city’s treatment resources, finding purpose and validation through this work. There was a consensus among many of the participants that the key to demystifying stigma is to share truths about mental illness with those who have not encountered it and to keep sharing their own stories whenever possible.

Calls to action

One point became quite clear over the course of the focus group discussions — having serious mental illness played a tremendous role in the course of each participant’s life, particularly in the decisions they made about their relationships and careers. Participants felt called to action by severe mental illness. They made references to their careers or future goals throughout the course of the conversations and, along similar lines, described feelings of empowerment, especially when discussing their relationships and the positive aspects of their mental illness.

Figure 11. Calls to action code frequency, by prompt

<table>
<thead>
<tr>
<th>Transcript section</th>
<th>Future goals code count</th>
<th>Empowerment code count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships and outlook</td>
<td>27</td>
<td>11</td>
</tr>
<tr>
<td>Positive aspects</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>Parenthood</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>General</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Crisis</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Treatment</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>62</td>
<td>30</td>
</tr>
</tbody>
</table>
Some participants did believe that their serious mental illness had a negative overall impact on their lives. However, the majority of participants were vocal about how their illness strengthened them and led them to their current vocations or advocacy efforts. Many participants cited their struggles with mental illness as the reason that they developed empathy for other people and the reason that they want to help others:

*I feel that living with my condition has given me insight into what other people go through and made me want to help. If it were not for my own challenges, I would not have gone back to help others.*

**Motivation for advocacy**

Several participants decided to devote their professional lives to advocacy as a result of their own experiences. One participant was in a leadership role at a nonprofit for a specific severe mental illness, another started her own nonprofit to advocate for those with serious mental illness and several others devoted their free time to advocacy and education efforts, including one woman who appeared in a documentary and does public speaking about mental illness.

There was a particular emphasis on storytelling and sharing personal stories as a means to advocate for others with serious mental illness. Some participants felt that they wanted to be able to give hope to people who were not at a stable point in their lives and educate the public about what living with serious mental illness is like and explain that recovery is possible.

*[One] of the positive points about having my serious mental illness is being able to educate other people about living with serious mental illness, whether it be young people, students in the college, in the high school [or] parents with children of serious mental illness. And I think that’s a very important, important part that we can do. I also think … sharing my story that no matter how far down the scale I get with my mental illness, recovery is possible.*

For this participant, motivation to share a story translated into a sense of empowerment about how she could impact the world and turn her experiences into a tool for others. It is important to note that almost all the participants have been living with their serious mental illness for several years, many for decades, and were at relatively stable points with their illness management. This likely played a large role in their positive outlooks and ability to advocate for others. But their stability also seemed to further motivate them to share their stories with others. This theme of empowerment because of their illness was directly tied to the call to action that many participants described:

*Being mentally ill makes me so much stronger. And it makes me a good advocate and a good mentor to be able to show people you can still be mentally ill and still achieve and do whatever you like in this life, whether it’s being a mother, an entrepreneur or any other thing you want to do in this life.*

So many of the participants were able to reflect on their long histories with their serious mental illness and the hardships that accompanied it and still find hope and drive to help others in a similar situation. The majority of the participants felt hopeful about the future and their own abilities to impact serious mental illness advocacy for the better.
LIMITATIONS

This study had several limitations. The relatively small sample size of 12 individuals, while common in qualitative research, means that the results cannot necessarily be generalized to represent the experiences of all women with serious mental illness.

Participants were recruited through previously established networks of family members and advocates at the Treatment Advocacy Center, meaning the participants may share qualities that affect generalizability. This generalizability was further hindered by the primarily white racial breakdown and the relative economic stability of the participants, meaning that none of the participants were currently homeless and they all had access to a computer or tablet and Wi-Fi to participate in the session. Additionally, all women interviewed were in a relatively stable state of their serious mental illness and were all receiving some degree of treatment. Many people with severe mental illness are currently untreated, which also affects their economic stability. In fact, some women were unable to participate because of a period of instability in their illness. Thus, we cannot say that the experiences of these women are generalizable to the broader population. However, many of the participants had previously experienced lengthy periods of instability, homelessness, incarceration and lack of treatment, which does allow for some generalization to others who may currently be experiencing these issues.

There was also a high rate of attrition. Originally, a total of 30 participants signed up for one of the two focus group sessions, but only 11 attended, with one more participant responding in written form after the focus group. The attrition may be attributable to a few factors, including the fact that individuals with serious mental illness often experience disordered thinking and have difficulty keeping track of appointments. To mitigate attrition, after initial registration, participants were notified by email which focus group session they would attend and were asked to save the date. One week before the session participants were reminded about the upcoming focus group with information about expectations for the discussion, the Zoom link and instructions for joining by computer or phone. Participants were reminded again four hours before the sessions began.

After many reminders and email correspondence before the sessions, some potential participants sent emails at the last minute saying they were unable to attend their designated times after realizing the meeting did not take place in their time zone. The sessions were conducted virtually over Zoom, which, though necessary due to COVID-19 safety protocols, may have been another barrier to participation. Two individuals attempted to join the sessions, but after failing to successfully troubleshoot the connection issues, were unable to participate. To try to be more inclusive, we offered individuals the option of providing written responses to the prompts as a way to participate. Only one individual submitted her responses that way.

In future studies of individuals with severe mental illness, researchers should take extra steps to ensure that participants are reminded of the date and time and are able to attend the session. Researchers should also consider creative ways to troubleshoot connection issues with participants ahead of time if they conduct sessions virtually. For example, we worked with the adult child of one participant to help set up Zoom on a tablet for the participant.
POLICY RECOMMENDATIONS

Women with severe mental illness face significant structural and institutional biases against their gender in addition to the biases that all people with severe mental illness experience, creating large barriers to treatment. Research sometimes fails to account for differences in experience by gender and women often have a harder time accessing proper treatment because care facilities are segregated by gender.

A policy response must recognize these fundamental barriers and seek to educate those in the medical field — and society as a whole — about where and why these barriers exist. Women with severe mental illness are some of the most marginalized members of our society and we must work to ensure that their voices are heard and that their needs are met.

TREATMENT ADVOCACY CENTER PROPOSES THE FOLLOWING POLICY RECOMMENDATIONS:

■ **Continue research on women-specific issues related to serious mental illness, including seeking more firsthand accounts from women.**

There are significant gaps in the existing body of research on women’s unique experiences with serious mental illness. Historically, women and other minorities have been left out of drug trials and clinical research on medications that directly affect their treatment trajectories, symptom reductions and experiences of side effects. Prioritizing women-specific issues will help reduce these gaps in research and increase the utility of treatments for women with severe mental illness. This can be achieved in the following ways:

- Increase funding sources for researchers pursuing projects specific to women with severe mental illness, including funding projects through the Advanced Research Projects Agency for Health.
- Include more women and other minorities, including those in intersectional subgroups, in drug trials, with an emphasis on symptom and side effect variations that may occur due to gender.
- Fund clinical research on treatments for women with severe mental illness, such as estrogen therapies that do not have risky side effects.
- Enforce the 1993 Women and Minorities as Subjects in Clinical Research law, part of the NIH Revitalization Act of 1993.34

■ **Expand mental health infrastructure for women with serious mental illness.**

The current mental health treatment system is significantly underfunded and understaffed, with many people having to wait months or even years to receive necessary treatment. Women often face more barriers due to bias from health care professionals and lack of space in facilities that separate people by gender. Women living in rural communities also face geographic barriers to treatment, as these areas have far less access to treatment facilities. These issues should be addressed in the following ways:

- Fund and build more psychiatric treatment facilities, especially for women and people who identify as female, and ensure that bed space is available in proportion to the populations that require treatment.
- Expand treatment access in rural areas and provide transportation for individuals to...
access the closest treatment facility in their area.

- Increase the number of psychiatrists and social workers that focus on women’s issues by implementing strategies to incentivize these career paths and prevent and reduce staff burnout.\(^{25}\)
- Expand education and bias training for all health care professionals to increase empathetic care within treatment settings.

### Institute social policies that protect the lives and well-being of women with serious mental illness.

In addition to treatment, women with severe mental illness need access to a full continuum of care in order to ensure that they are able to access basic resources necessary for functioning in society. It is imperative that people with severe mental illness have their basic needs met, otherwise their treatment progress is much more likely to be impeded. Furthermore, research suggests that women with severe mental illness often face systemic discrimination that puts them at a higher risk for negative outcomes, like losing custody of their children.\(^{36}\) These issues should be tackled in the following ways:

- Establish more safe housing programs for women experiencing severe mental illness, including housing that supports women and their children.
- Create more support systems and increase access to social workers who can assist women with severe mental illness with children, with the goal of keeping parents and children together whenever it is possible and safe to do so.
- Reduce traumatic interactions with law enforcement by
  - training law enforcement on best practices for working with women experiencing mental health crises and
  - encouraging use of the 988 Suicide and Crisis hotline to divert mental health crisis calls to mental health professionals instead of police whenever possible.
- Reduce criminalization of mental illness by diverting women with serious mental illness away from the criminal justice system.
- Expand community programs that assist people with severe mental illness with signing up for, and understanding, the full benefits available from government programs and insurance plans.
- Conduct a Government Accountability Office investigation about how income eligibility limits for Medicare, Medicaid, Supplemental Security Income, Social Security Disability Insurance and other income supports inhibit employment opportunities for people with serious mental illness.

### Acknowledge and lift up voices of women in severe mental illness advocacy.

People with severe mental illness are some of the most marginalized individuals in our society. Their voices often go unheard, and this is particularly true for gender and racial minorities. Women’s issues should be included in severe mental illness advocacy, and policies that promote treatment for severe mental illness should be adopted by women’s rights advocacy groups. This can be achieved by following these recommendations:

- Create more platforms for women and other marginalized groups with serious mental illness to share their stories in advocacy efforts for serious mental illness and women’s rights.
- Support organizations that work to reduce gender inequity.
REFERENCES


11 Mizock & Lundquist. Missteps in psychotherapy with transgender clients.


32 Torrey. *Surviving schizophrenia*.  

33 Torrey. *Surviving schizophrenia*.  


The Treatment Advocacy Center is a national nonprofit organization dedicated exclusively to eliminating barriers to the timely and effective treatment of severe mental illness. The organization promotes laws, policies and practices for the delivery of psychiatric care and supports the development of innovative treatments for and research into the causes of severe and persistent psychiatric illnesses, such as schizophrenia and bipolar disorder.