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<https://behavioralhealthnews.org/severe-long-term-mental-illness-what-does-it-take-to-live-well/>

## **SEVERE, LONG-TERM MENTAL ILLNESS: WHAT DOES IT TAKE TO LIVE WELL?**

By

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Typical images of people with severe, long-term mental illnesses are misleading. We think not of people who, despite mental illness, have lives that they find satisfying and meaningful but of homeless people dressed in rags pushing shopping carts with all their belongings and sleeping on heating grates on city streets or people tormented by angry, domineering voices or people whose depression is so deep that they can't get out of bed in the morning or people who relive terrifying experiences over and over again or people who are also addicted to alcohol or drugs and whose lives have fallen into disarray.

It is true that people with serious, long-lasting mental illness are, by definition, unable to manage in the community without substantial assistance from family, friends, communities, and/or the government. It is also true that they frequently have difficult lives. Their life expectancy is 10-25 years less than the general population<sup>1</sup> in large part because they often have poor health and have limited access to decent health care.<sup>2</sup> They frequently have co-occurring substance use disorders.<sup>3</sup> They often live in poverty and in squalid and sometimes dangerous housing. They frequently experience homelessness at some point in their lives.<sup>4</sup> They are disproportionately among those incarcerated in jails and prisons.<sup>5</sup> They have high rates of suicide.<sup>6</sup> They are mostly unemployed.<sup>7</sup> They often have limited access to the mainstream—even to houses of worship.<sup>8</sup> And so on.

Despite this bleak picture, many people with severe, long-term mental illness have lives that they find satisfying and meaningful and, in that sense, have experienced what has come to be called "recovery".<sup>9, 10</sup> Notably, some people with serious mental illness are now working as peer specialists,<sup>11</sup> and there are some who have emerged as advocacy leaders and as managers of mental health organizations.

What does it take for people with SPMI to have satisfying lives in the community? The answer is not difficult, because people with SPMI are first and foremost people, and all people have the same fundamental needs:

- A decent place to live
- Income to pay for food, other necessities, and a bit of fun
- Health and longevity
- Satisfying family and social relationships
- Satisfying and meaningful activities such as work or art or advocacy
- A sense of connection and belonging in a community they value
- Spiritual opportunities.

The survival of people with severe, long-term, disabling mental illnesses, is historically the core responsibility of the American mental health system. From the end of the 18<sup>th</sup> century until the middle of the 20<sup>th</sup> century, this responsibility was met primarily by providing custodial care in state asylums and hospitals. After World War II, a gradual shift began to support this population in the community. There were changes both in mental health policy and, perhaps more importantly, in policy regarding public assistance, which became available to people with psychiatric disabilities early in the 1950s.<sup>12</sup> Reliance on state hospitals peaked in 1955, when at most 1/3 of people with severe, long-term mental illness were in state hospitals. Incremental changes over the past 60 years, especially the development of the Community Support Program (CSP), have resulted in important improvements in the lives of people with psychiatric disabilities. There has been significant growth of mental health services for people with severe, long-term mental illness. Nearly 2/3 of them now get treatment and other services that go beyond the provision of medication and verbal therapy and also include supportive housing, day programs, psychiatric rehabilitation, and case/care management, all mostly outside of state hospitals.

Nevertheless, about 35% of people with serious mental illness do not get any treatment,<sup>13,14</sup> more among people of color.<sup>15</sup> And there are significant problems with the quality of treatment they do get. It frequently is not even “minimally adequate”,<sup>16</sup> and it is often fragmented and chaotic.

So, there need to be vast improvements, including:

- more effective psychiatric treatment,
- more widespread psychiatric rehabilitation,
- more personalized care management,
- more humane crisis intervention,
- outreach to find people who do not come to designated places for care and to connect with them before they are in crisis,
- a more just criminal justice system, and
- greater respect for their rights as human beings.

There is widespread agreement about all this, but there are significant details that are incredibly complicated and controversial. For example, and most prominently, there is disagreement about whether more

people with serious, long-term mental illnesses need inpatient hospital care and about whether coercive interventions should be used more extensively for people reluctant or unable to use organized mental health services. Some argue in favor of increased coercion so as to reduce homelessness and incarceration. Some maintain that increased outreach and engagement and expansion of community support services, especially housing, would be far more effective.

Unfortunately, the dispute between those who favor more hospitalization and coercion and those who oppose it dominates the headlines about mental health policy. As I've said, there is considerable agreement about the need for more and better treatment, rehabilitation, and community support services, and I have argued for many years that the mental health community should unify around these areas of agreement so as to become a more effective advocacy force.<sup>17</sup>

But unity is difficult to achieve in large part because of differences in fundamental perspectives about serious mental illness. Many advocates and providers have a "treatment-oriented" perspective. Others have what has come to be called a "recovery-oriented" perspective.<sup>18</sup> The difference is that from one perspective the primary question is what services (especially treatment services) people with serious mental illness need. From the recovery perspective, the key question is what people with SPMI need to lead satisfying lives in the community. The answers to the two questions overlap, but the services-oriented perspective emphasizes the need for treatment, rehabilitation, supportive housing, care management, and the like while the recovery-oriented perspective emphasizes, to say it again, the need for a decent place to live, income for necessities, good physical health, satisfying family and social relationships, meaningful activity, and spiritual life in addition to mental health services.

One way to think about this difference in perspectives is that typically mental health policy focuses, quite understandably, on needs due to abnormality. The alternative is to focus as well on the fundamental humanity of people with serious mental illness, on the needs and desires they share with others, on their—this may seem strange—normality.

People with serious, long-term mental illness can have lives that they find satisfying and meaningful. Helping them have such lives should be the first goal of mental health policy.

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- <sup>1</sup> [Mortality gap and physical comorbidity of people with severe mental disorders: the public health scandal | Annals of General Psychiatry | Full Text \(biomedcentral.com\)](#)
  - <sup>2</sup> [Severe mental illness and health service utilisation for nonpsychiatric medical disorders: A systematic review and meta-analysis | PLOS Medicine](#)
  - <sup>3</sup> [A 16-year follow-up of patients with serious mental illness and co-occurring substance use disorder - PMC \(nih.gov\)](#)
  - <sup>4</sup> [The Never-Ending Loop: Homelessness, Psychiatric Disorder, and Mortality \(psychiatrictimes.com\)](#)
  - <sup>5</sup> [smi-in-jails-and-prisons.pdf \(treatmentadvocacycenter.org\)](#)
  - <sup>6</sup> [Suicide in Schizophrenia: An Educational Overview - PMC \(nih.gov\)](#)
  - <sup>7</sup> [Mental Illness: NAMI Report Deplores 80 Percent Unemployment Rate; State Rates and Ranks Listed—Mode | NAMI: National Alliance on Mental Illness](#)
  - <sup>8</sup> [The Silent Stigma of Mental Illness in the Church | Sojourners](#)
  - <sup>9</sup> [Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. - PsycNET \(apa.org\)](#)
  - <sup>10</sup> [Triumph of Recovery.pdf \(michaelbfriedman.com\)](#)
  - <sup>11</sup> [Peers | SAMHSA](#)
  - <sup>12</sup> Frank and Glied *Better But Not Well*, Chapter 4.
  - <sup>13</sup> [NIMH » Mental Illness \(nih.gov\)](#)
  - <sup>14</sup> [Key Substance Use and Mental Health Indicators in the United States: Results from the 2020 National Survey on Drug Use and Health \(samhsa.gov\)](#)
  - <sup>15</sup> SAMHSA (2021) [Racial/Ethnic Differences in Mental Health Service Use among Adults and Adolescents \(2015-2019\) \(samhsa.gov\)](#) Chapter 5
  - <sup>16</sup> [\(PDF\) Twelve-Month Use of Mental Health Services in the United States: Results From the National Comorbidity Survey Replication \(researchgate.net\)](#)
  - <sup>17</sup> [Put Ideological Differences Aside Final.pdf \(michaelbfriedman.com\)](#)
  - <sup>18</sup> [Triumph of Recovery.pdf \(michaelbfriedman.com\)](#)