



# Shattered Lives

## Results of a National Survey of NAMI Members Living with Mental Illnesses and Their Families

THE MENTAL HEALTH SYSTEM is in shambles resulting in the shattered lives of individuals living with serious mental illness depicted in a national survey of 3,430 NAMI members.<sup>1</sup> The results show a disenfranchised group of Americans whose lives have been placed on hold as they engage in a frustrating attempt to manage their illnesses in the absence of effective services that can make recovery a real possibility.

### People Disenfranchised by a Shambled System

While the individuals represented in the survey are working age adults with a serious mental illness, they are largely alone, unemployed, impoverished and dependent on public programs. And all too often, these individuals come into the hands of the criminal justice system.

- Eighty-six percent of the individuals represented in the survey are between 18 to 54 years of age.
- Most—62 percent were not married; 31 percent lived alone and 25 percent lived with their families.
- Fifty-two percent of the individuals represented in the survey were diagnosed with schizophrenia, 42 percent bipolar disorder, and 28 percent major depression; 57 percent received more than one diagnosis in their lifetime.
- Just over two-thirds—67 percent—were unemployed.
- Medicaid and Medicare were the primary forms of health insurance among individuals represented in the survey, as 37 percent of respondents identified one or both as their form of health insurance coverage. Still, 37 percent also relied on private health insurance and ten percent reported no health insurance coverage at all.
- Seventy-one percent live on less than \$20,000 a year, and one in five live on less than \$5,000 year. Income sources included SSDI (37 percent); SSI (35 percent); wages from a job (30 percent); and regular support from family members (19 percent).
- Forty-four percent had been arrested at some point in their life, for 29 percent of individuals the arrest occurred in the past year—and many of these did not receive appropriate treatment while incarcerated.

<sup>1</sup>Hall, L.L., Graf, A.C., Fitzpatrick, M.J., Lane, T., and Birkel, R.C., *Shattered Lives: Results of a National Survey of NAMI Members Living with Mental Illnesses and Their Families* TRIAD Report, NAMI, Arlington, VA, 2003.

### Voices from the TRIAD Report:

*Until 2 months ago, I had been unemployed and unable to work due to serious mental health problems ... For 21 of those 22 years, I have depended on SSDI and SSI for support, which combined, now provides me \$572 a month...I know poverty first hand...I have faced numerous barriers to employment...and I also face losing SSDI and Medicare if I continue working...What should I give up? My recovery? Productive work? Access to mental health treatment? Additional income supports that permit me to eat every day and stay in my apartment?*

### Voices from the TRIAD Report:

*The jail system here is really bad. They do not give people their meds...the psychiatrist at the regional jail either doesn't order the person's usual medications or changes the whole regimen...or perhaps doesn't order them anything at all.*

Almost half of those receiving supported employment services last year ranked their quality and accessibility as poorest of all the interventions.

- ACT services were accessed by even fewer individuals, with less than 20 percent ever accessing this intervention.
- Consumer-run programs, among the most highly rated in terms of quality, were received by only about one-third of the individuals represented in the survey.

### Voices from the TRIAD Report:

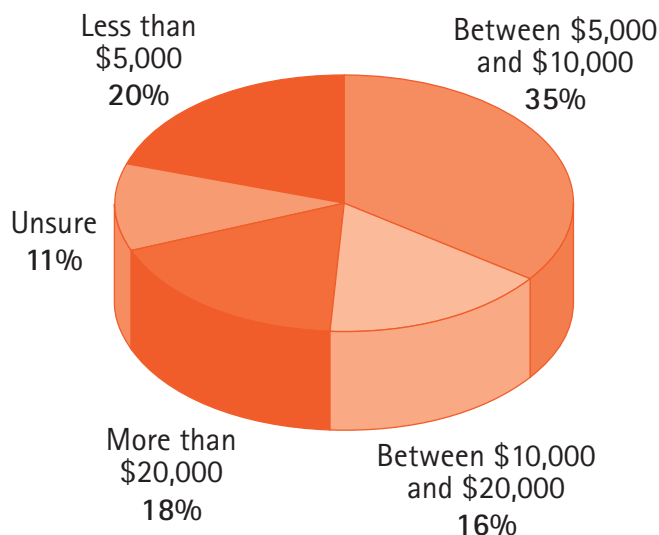
*Community supports for consumers and families in rural areas are very limited. There is a severe shortage of psychiatrists...as well as nurses who do psychiatric home care. [There is only] a single ACT team in the city...[yet] last summer...we discharged 30 people to the community knowing there was no...service available to them. It was frightening and very unfair to the consumers.*

## Lack of Recovery-Oriented Services

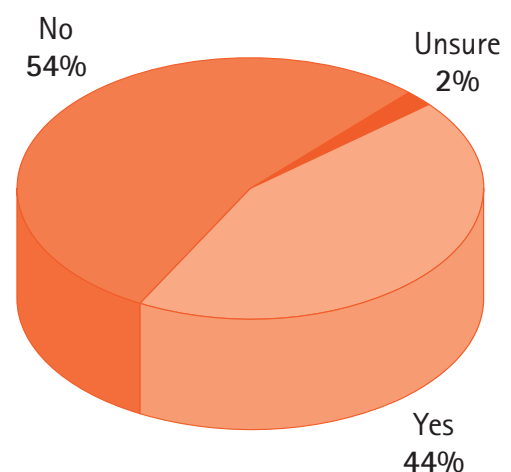
The individuals represented in the survey typically accessed traditional mental health services— medication, psychotherapy, hospital care, and emergency treatment—which is no surprise since most failed to obtain quality evidence-based interventions shown to prevent crises and promote recovery— Assertive Community Treatment programs (ACT), supported employment, integrated substance abuse and mental health treatment, and consumer-provided services.

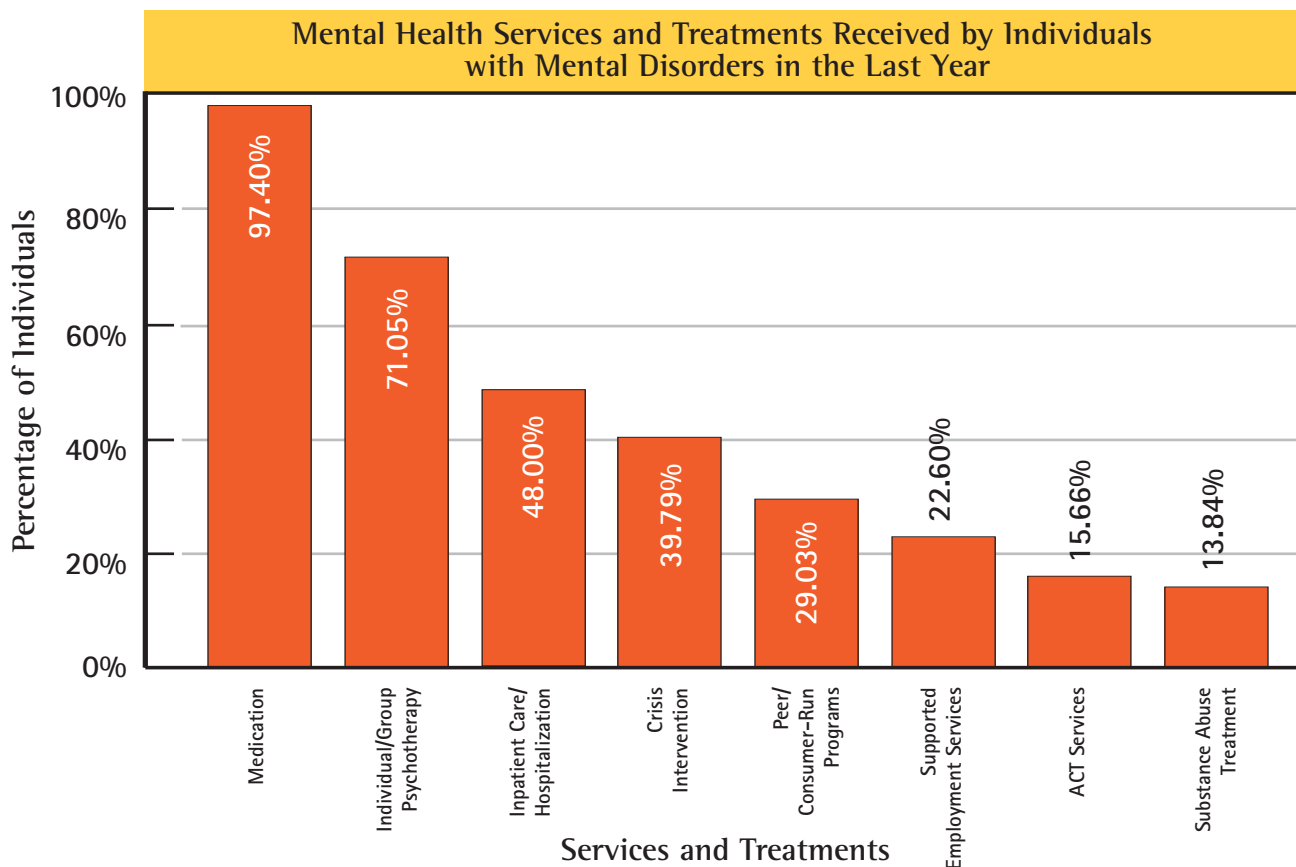
- Only 23 percent of the individuals received supported employment services in the last year; only 28 percent ever received such services.

Annual Income for Individuals with Mental Illness



Have You Ever Been Arrested or Detained by the Police?





## A Myriad of Barriers to Recovery

In addition to the lack of quality services, the TRIAD survey shows that stigma, discrimination, costs, lack of supports, and inane disincentives in public programs create daunting barriers to recovery.

- Stigma and discrimination was the most commonly cited barrier to employment, with nearly half of the respondents identifying this obstacle.
- Fear of losing health insurance or disability income was identified as a barrier to work by 40 percent of the respondents.
- More than half of the respondents reported costs as a significant barrier to appropriate and stable housing.
- The lack of supports and appropriate services were commonly identified barriers to both housing and employment.

## Families Suffer Too

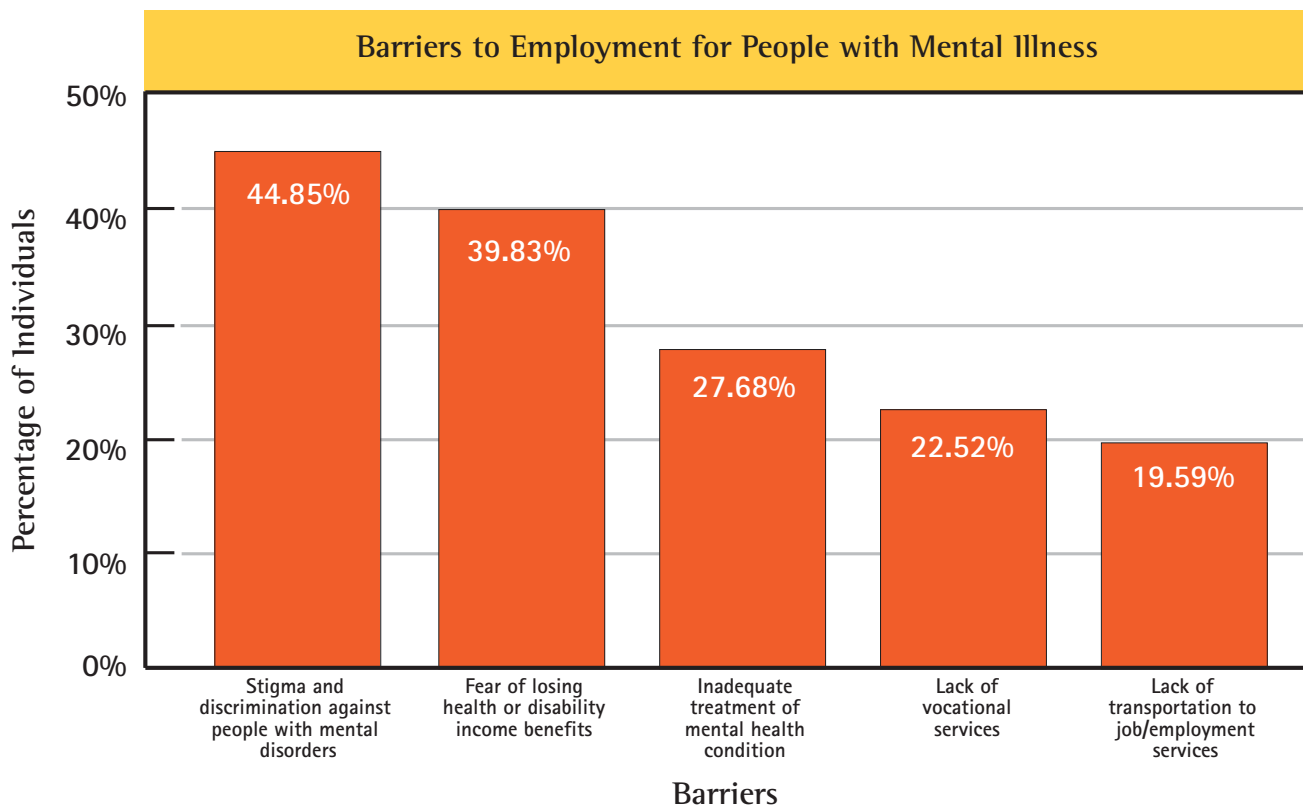
Families of people with serious mental illness in the survey have been forced to fill the service gap within the mental health system. Many individuals represented in the survey depend upon their families for medical care, money, housing, and emotional support. As families step in to support their loved ones, they

## Voices from the TRIAD Report:

*Stigma and discrimination have cost me my livelihood, self-esteem and the future I had before I self-disclosed my illness. I hadn't changed, but what the world saw had: after knowing about my illness they saw someone who is unemployable, undependable and possibly dangerous; a person who cannot be trusted.*

often do so without receiving any education about mental illness and support—services highly valued by families and shown to help them cope.

- Twenty-five percent of individuals with mental illness represented in the survey live with their parents.
- Nineteen percent of the individuals represented in the survey receive financial support from their families on a regular basis.
- Despite this heavy dependence on families, only slightly more than half—54 percent—of family members represented in the survey received family education and support services in the past year.
- Eighty-five percent of those participating in NAMI's Family-to-Family program found it extremely helpful.



## Ending the National Disgrace

We know how to reform the mental health system so as to make it a fair and effective one. But such reform—that makes recovery a reachable goal for all individuals living with serious mental illnesses—requires nothing less than a revolution. The steps to creating a recovery-oriented mental health system include:

- The broad expansion of peer-provided services for individuals with serious mental illnesses and their families;
- The full implementation of evidence-based, recovery-oriented interventions including ACT programs, supported employment, integrated treatment of substance abuse and mental illnesses, and appropriate medication;
- Adequate funding of effective programs;
- An end to discrimination in employment, housing, and health insurance;
- Reform of public policies that obstruct work and appropriate housing;
- An accountable system that documents expenditures, services, and outcomes achieved by individuals living with mental illnesses;
- Advocacy to end the disgraceful treatment of people living with mental illnesses.

**JOIN US TODAY** to end the national disgrace that is our nation's mental health system. Visit NAMI's website at <http://www.nami.org> to learn more about TRIAD and how you can become a part of this critical effort.