



**TRIAD**

Treatment/Recovery Information  
and Advocacy Database

# Shattered Lives



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



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Living with Mental Illnesses and Their Families



Treatment/Recovery Information and Advocacy Database

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# Executive Summary

Seventy-one percent reported an annual income of \$20,000 or less; nearly 20 percent reported less than \$5,000 in annual income. Two-thirds were unemployed. More than half rely on public programs. In the last year alone, nearly half were hospitalized. Forty-percent sought emergency care last year. Forty-four percent reported being arrested or detained by police.

This is the portrait of people with serious mental illnesses painted by the results of a national survey of NAMI members conducted early in 2003, which launched our broad initiative—TRIAD, Treatment/Recovery Information and Advocacy Database—to monitor the mental health system and its outcomes. More than 3,400 individuals with serious mental disorders and their families from all 50 states responded to the questions about mental health, treatment and service access and quality, and their living situation.

These results depict a disenfranchised group of Americans in the prime of their lives—86 percent were between the ages of 18 and 54—struggling with serious mental illness without the benefit of needed services and supports. The tragedy of these results is that they are avoidable. Few of the respondents reported access to recovery-oriented, scientifically proven interventions, such as supported employment, assertive community treatment (ACT) programs, and substance abuse treatment (23 percent, 16 percent, and 14 percent respectively, in the last year). Between 30 and nearly 50 percent of those who did manage to obtain these services found serious problems in terms of access, timeliness, quality, and safety.

Not only did the individuals with serious mental

disorders and their families represented in this survey face a lack of access to quality interventions that have been shown to promote recovery and employment; they also confronted barriers of stigma, discrimination, public policies that discourage work, and inadequate health insurance coverage. Among the few optimistic results to emerge from this study was the positive impact of peer-provided services, including consumer-run programs and family education and support. Still, less than one-third to one-half of the respondents had access to these effective and valued interventions in the last year.

The data from this survey show that the mental health system is not only in shambles, but is a national disgrace, resulting in the shattered lives given voice to in the pages of this report. These results stem from failed public policy, the absence of effective programs and services in many communities, and continuing stigma and discrimination. Thus, these results are largely avoidable. This report calls on federal and state policy-makers to immediately set national mental health policy on a course that broadly implements peer-provided services for individuals with mental disorders and their families and significantly expands services shown to promote recovery, with adequate funding and public accountability. NAMI also calls on policy-makers to end discriminatory policies in health insurance, employment, and housing and to end the powerful disincentives to work that persist in public income replacement and health insurance programs. We call on all stake-holders, including individuals with mental illnesses, their families, advocates, providers, policy-makers, and the tax-paying public to join NAMI in working for the much needed and achievable revolution in the mental health system.

# Introduction

NAMI—the National Alliance for the Mentally Ill—was founded in the wake of a public health crisis in the United States. Between the years of 1970 and 1980, 257,584 public psychiatric hospital beds were shut down.<sup>1</sup> Few services were established in communities for people leaving the hospitals.<sup>2</sup> Homelessness, incarceration, and criminal victimization were the fate of hundreds of thousands of individuals living with severe mental illnesses.<sup>3</sup> The first national survey of NAMI members, in 1990, showed that for many individuals, families quietly filled the vacuum, becoming the principal and usually unaided care-givers.<sup>4</sup>

During the intervening years, significant achievements have been made. New treatments have been developed; research has established the effectiveness of services that promote independent community living, recovery, and employment for adults living with even the most disabling and chronic mental illnesses; public programs have been developed to help meet the housing and income needs of people living with a mental illness; and the consumer and family movements have flourished.<sup>5</sup> Leaders in government, health care, and the scientific community have declared that we have the tools to free people who have severe mental illnesses from relentless disability, mental health crises, and marginalization. With the right treatments and supports and an end to stigma and discrimination, people living with mental illnesses and their families were told to expect greater productivity and quality of life.

Evidence suggests that this promise has not been realized.<sup>6</sup> Most people with mental illnesses do not have access to needed and appropriate mental

health care. Unemployment, imprisonment, homelessness, abuse, social isolation, and untimely deaths are still the outcomes that many people experience. The current Presidentially-appointed body, the New Freedom Commission on Mental Health, declared the mental health system to be in shambles in its interim report, exacting a toll not only on individuals and their families, but on the nation and its economy as well—costing \$63 billion annually in lost productivity alone.<sup>7</sup>

In response to the continuing crisis of mental health care, NAMI has launched a large scale monitoring project, TRIAD—Treatment/Recovery Information and Advocacy Database—to examine and hold policy-makers and providers accountable for the implementation of effective treatments and services in each state and the outcomes achieved. The first TRIAD project surveyed NAMI's own members nationwide to assess their experience of severe mental illnesses, the services received, and the outcomes realized. This report, the first in a series, documents the national results from this survey.

The results are extremely troubling. Most people living with mental illness represented in this survey do not have access to the community-based, recovery-oriented, effective interventions envisioned by scientific, clinical, and government leaders. Instead, individuals living with these illnesses have become impoverished, socially marginalized, and unemployed; they frequently find themselves accessing hospital and crisis services; as a last resort, often find themselves in the custody of the criminal justice system, as they struggle to find effective treatment. Family members and friends continue



to fill the service system gap, most often unaided, and they continue to worry about the well-being of the person they love when they are no longer available to provide the necessary care, support, housing, and finances.

In the last 25 years, since NAMI was created, most people with mental illnesses have been freed from the walls of decrepit state mental hospitals. But, instead of freedom, dignity, independence, and recovery in the community, people with serious mental illnesses have found their lives shattered and placed on hold as they engage in an endless and futile attempt to manage their illnesses without the services and supports that make that possible. It is the goal of NAMI and TRIAD to bring the full range of interventions that work to people with severe mental illnesses and their families, through information, education, monitoring, and advocacy.

## Methods

Under a grant from the Stanley Medical Research Institute, NAMI contracted with Aspen Systems Corporation to design, implement, and analyze a survey of NAMI members so as to collect information on mental health diagnoses, services and treatments; health insurance status, current living arrangements and barriers to securing appropriate housing; employment and barriers to work; criminal justice system involvement; family support and education; and demographic information on race, ethnicity, education, income, and marital status. Data were collected regarding first-hand experiences from individuals with mental illnesses who are members of NAMI and from family members who belong to NAMI.

### Survey Methodology

NAMI staff worked with researchers at Aspen

Systems Corporation to develop a survey for NAMI members. The final survey contained a total of 24 items across nine main categories, including: status identification (individual with a mental illness, family member, or other); mental health diagnosis; service history; evaluation of services; non-mental health conditions; living situation and employment status; criminal justice system involvement; peer education and support; and, background demographic information. The survey questions were informed by the previous survey of NAMI members conducted by Johns Hopkins University School of Public Health as well as services shown to be effective by research. A draft survey was reviewed by the TRIAD steering group<sup>8</sup> and piloted at a drop-in center in Alexandria, VA and by NAMI state TRIAD leaders. Final revisions were made based on this input. Paper and online versions of the survey were prepared (Appendix B).

A sampling frame was developed from the NAMI membership database in early January, 2003. A total of 37,406 individual NAMI members were identified for sampling, including 7,516 individuals with a mental illness and 29,890 family members. The sample employed a stratified design, by state and member class. A simple random sample of members was selected within each state by member class stratum, with the same sampling fraction used for selecting both individuals with a mental illness and family members within a state. The sample was designed to produce national level estimates by member class and overall state-level estimates with specific confidence levels and precision. At the national level, this design produces overall estimates of survey proportions having a precision of  $\pm 1.5$  percent or better and estimates by member class having a precision of  $\pm 3.0$  percent or better, at the 95 percent confidence level. The target response was 4,000 members.

NAMI mailed surveys to 7,952 members on February 27, 2003. The survey was made available

online on February 28, 2003. The password-secured, web-based version was intended to provide respondents with the option of using the Internet to respond to the survey. The survey period extended until May 5, 2003. Aspen logged and tracked surveys returned to NAMI as well as undeliverable surveys for accurate tracking of non-respondents. To protect the confidentiality of the respondents, the survey contained no respondent name or other identifying information. A unique ID number assigned to each survey was used to enter that data and coded text entries into a database. All survey responses were integrated in a SAS system file. A series of quality control procedures were used to ensure that the data were recorded and stored accurately.

Several strategies were implemented to maximize survey response rates, including a pre-survey letter sent two weeks prior to the mailing of the surveys; reminder postcards mailed to survey recipients two weeks after the surveys were distributed; and follow-up telephone calls to non-respondents from April 7th through the 23rd. NAMI staff and volunteers, including members from five states, conducted the follow-up calls with guidance from Aspen.

Based on the combined mail and online returns, and the elimination of ineligible (undeliverables and health care professionals), the overall response rate for the survey was 45 percent. Responses were obtained from 3,430 NAMI members. A sampling weight was attached to each respondent, calculated as the product of two factors: an initial sampling weight (the reciprocal of the initial probability of selection) and a nonresponse adjustment.

## Data Analysis

NAMI and Aspen staff developed an analysis plan with 11 primary research questions. National

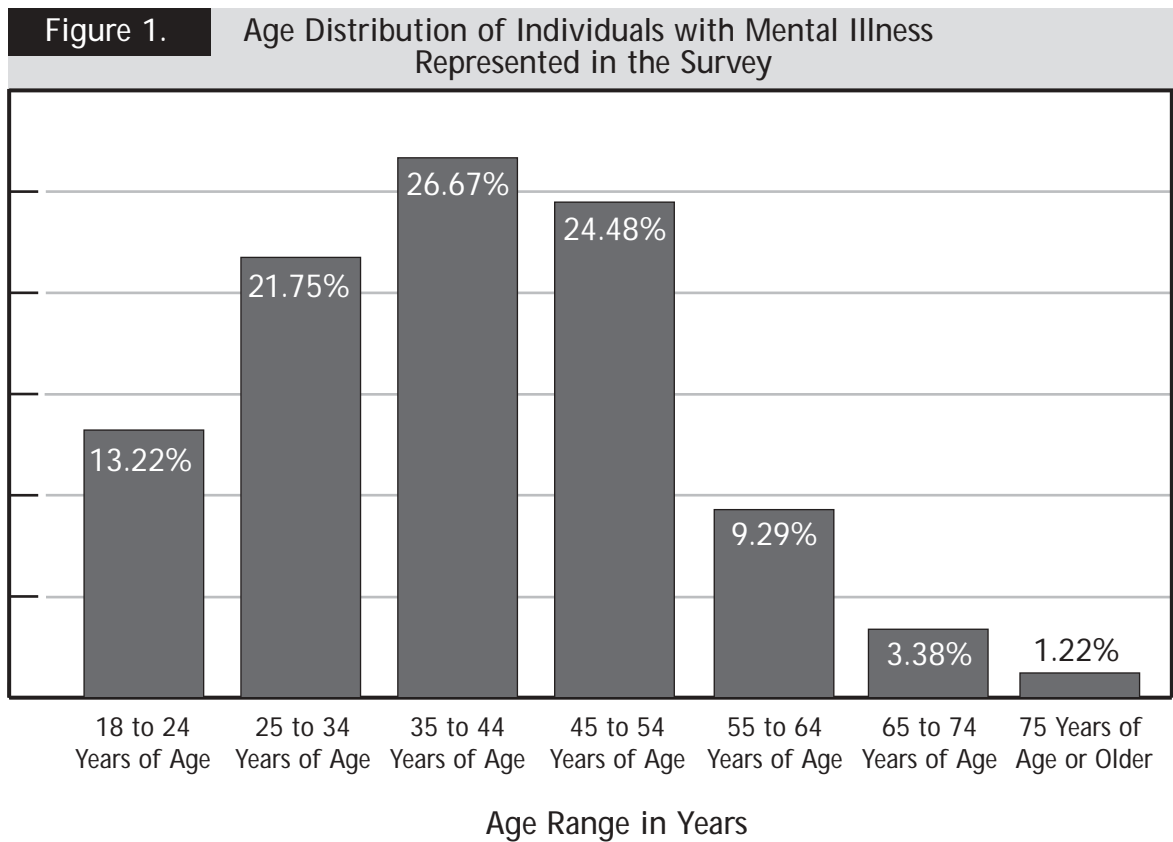
level analyses were based on weighted frequency distributions. Future reports will detail analyses of geographical region responses and distinctions between consumer and family member responses. Summary statistics are provided in this report.

## Results

The data summarized below reflect the views of survey respondents: NAMI members—both individuals with a mental illness and family members—provided information about the experiences of individuals with severe mental illnesses and their family members. In other words, NAMI members who are consumers answered the survey questions pertaining to an individual with a mental illness about their own experiences and answered survey questions pertaining to family member education and support about their family members. Family members who responded to the survey reported on the experiences of an individual with a mental illness in their family and their own experience of family education and support.

## Survey Respondents

Of the 3,430 usable surveys obtained, 86 percent of the respondents completed the paper survey and 14 percent responded online. Seventy-nine percent of the members reported being a family member or friend or care-giver of a person with a severe mental illness. The remaining 21 percent of members are individuals with a mental illness. Responses were received from all 50 states and the District of Columbia. The majority of members indicated that they have been members of NAMI for five years or less—61 percent of the 3,301 individuals responding to this question.



***The vast majority of individuals with a mental illness represented in the survey were adults of working age—eighty-six percent of the 3,361 respondents to this question on the survey were between the ages of 18 and 54.***

**Table 1. Marital Status and Educational Achievement of Individuals with Mental Illness Represented in the Survey**

Marital Status	Percent of 3,377 Total Individuals
Married	17.63
Widowed	2.31
Divorced	16.03
Separated	1.80
Never Married	62.23
Highest Level of Education	Percent of 3,403 Total Individuals
Less than high school	3.66
Some high school	5.67
High school graduate/G.E.D. recipient	22.74
Some college	31.64
Undergraduate degree	15.55
Some graduate school	4.29
Graduate degree	11.13
Vocational/career development training	1.98
Vocational school certificate or diploma	2.98
Other	0.37

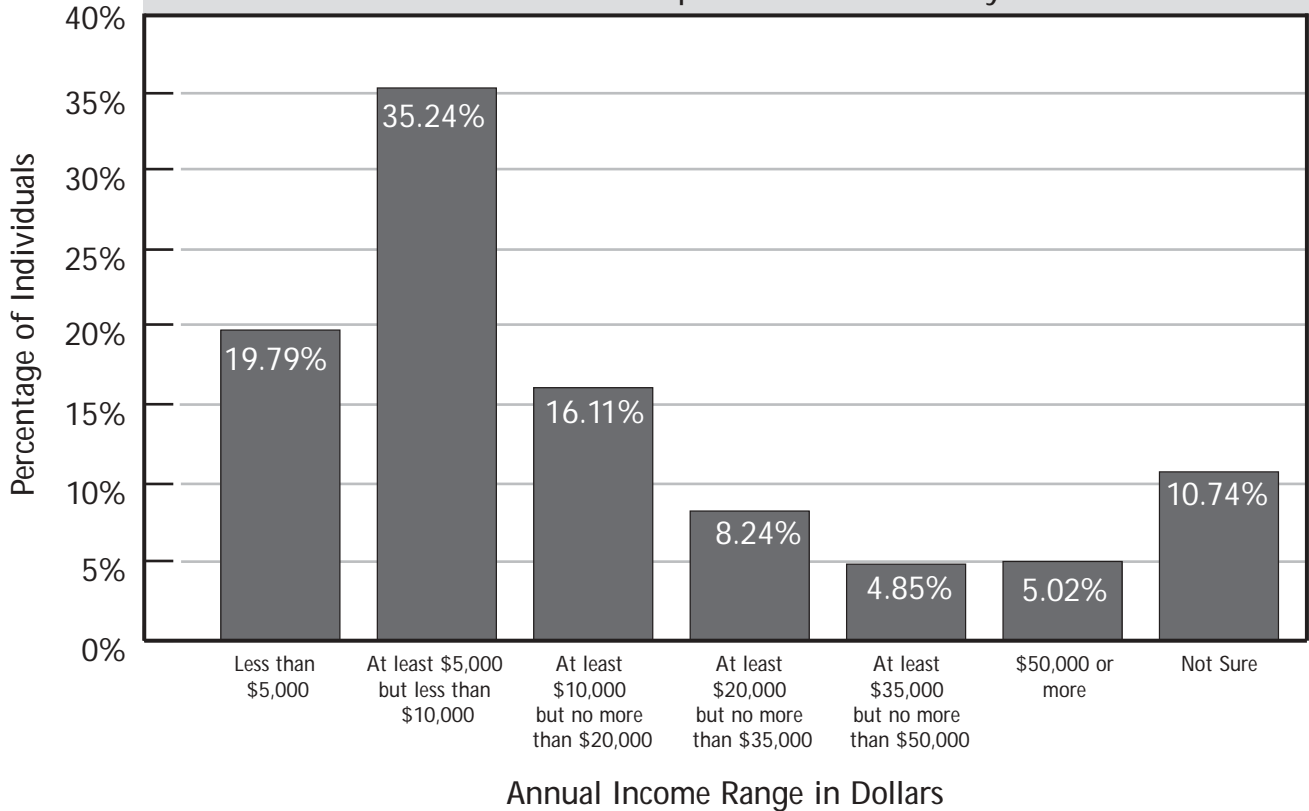
### Demographics of Individuals with Mental Illness

Well over half of the people with mental illness represented in the survey are between the ages of 18 and 44 years of age—62 percent of the 3,361 respondents to this question (figure 1). Eighty-six percent were between the ages of 18 and 54 years of age. Most of these individuals were male, 58 percent of the 3,375 respondents to this question, and 94 percent of the 3,395 respondents were white.

Most of the people with mental illness represented in the survey data have never married—62 percent. Sixteen percent were divorced and 18 percent were currently married (table 1). Fifty-five percent of the individuals obtained only a high school education or equivalency degree or received only some education at the college level. Still, 16 percent earned an undergraduate degree and an additional 15 percent received some graduate school education or a graduate degree.

**Figure 2.**

**Annual Income of Individuals with Mental Illness Represented in the Survey**



**Nearly three quarters of the individuals with mental illness represented in the survey, based on 3,264 responses to this question, had a reported annual income of \$20,000 or less.**

**Table 2. Income Source of Individuals with Mental Illness Represented in the Survey**

Income Source	Percent of Individuals with Mental Illness (based on 3,152 total responses)
SSDI	37.03
SSI	34.76
Wages or Salary from Job	29.57
Money on a Regular Basis from Family	19.26
Other Sources	9.34
Household Income from Spouse	6.31
Retirement	5.82
State Income Supplements	4.87
VA Benefits	2.76
Unemployment Benefits	1.55

Nearly 20 percent of the people with mental illnesses represented in the survey had an estimated annual income of \$5,000 or less (figure 2). Fifty-five percent of the individuals received an approximate annual income of \$10,000 or less, and 71 percent received an estimated \$20,000 or less each year. Primary sources of income include: Social Security Disability Income (SSDI)—37 percent; Supplemental Security Income (SSI)—35 percent; wages or salary from a job—30 percent; and money on a regular basis from family—19 percent (table 2). Forty percent report income from multiple sources, most frequently regular family support augmenting SSI, SSDI, or wages earned from a job.

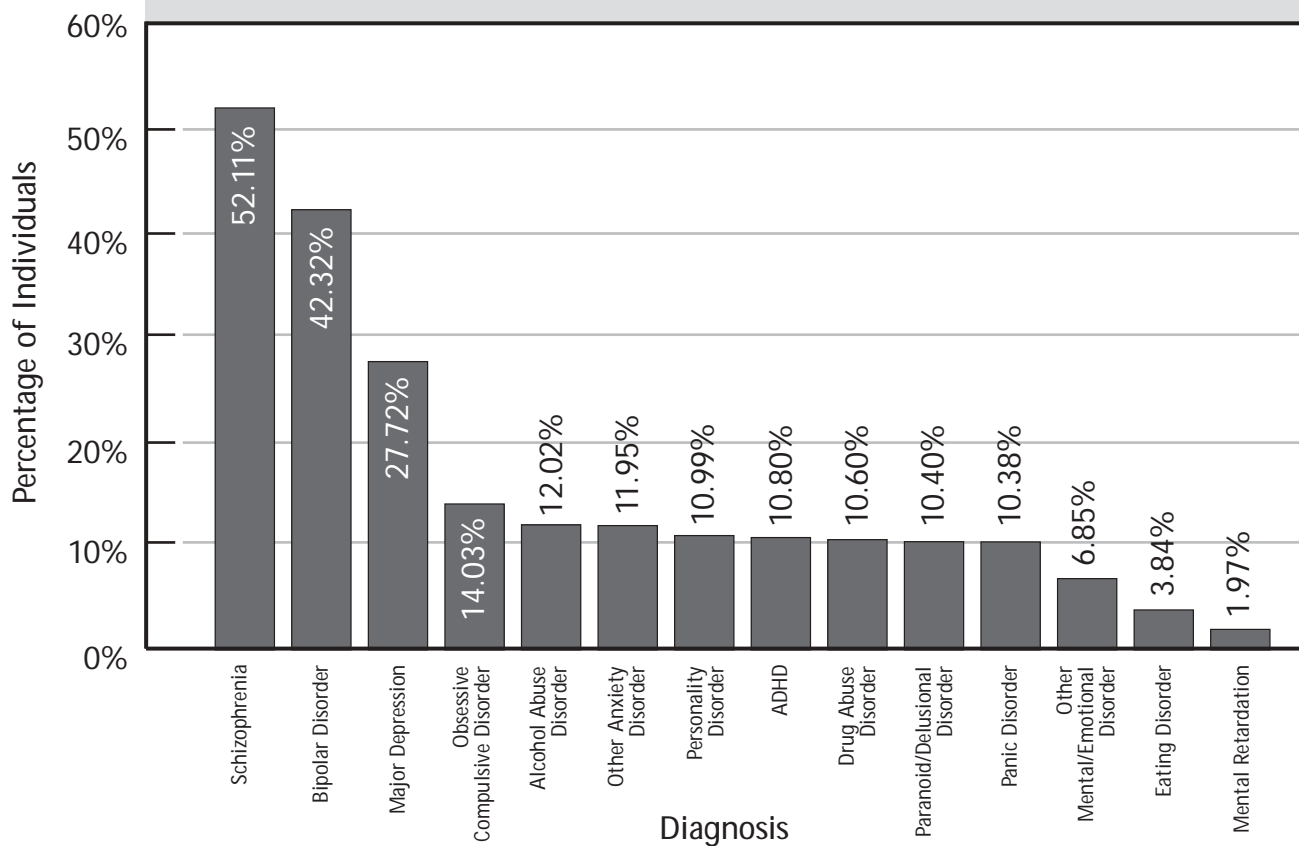
**Table 3. Health Insurance Coverage of Individuals with Mental Illness Represented in the Survey**

Health Insurance Coverage	Percent of Individuals (3,352 total responses to the question)
Medicaid	37.38
Medicare	37.28
Private Health Insurance Provided through Employer	23.83
Self-Purchased Private Health Insurance	12.57
No Insurance	9.63
Other	7.41
Not Sure	3.49
Veterans Administration	3.32

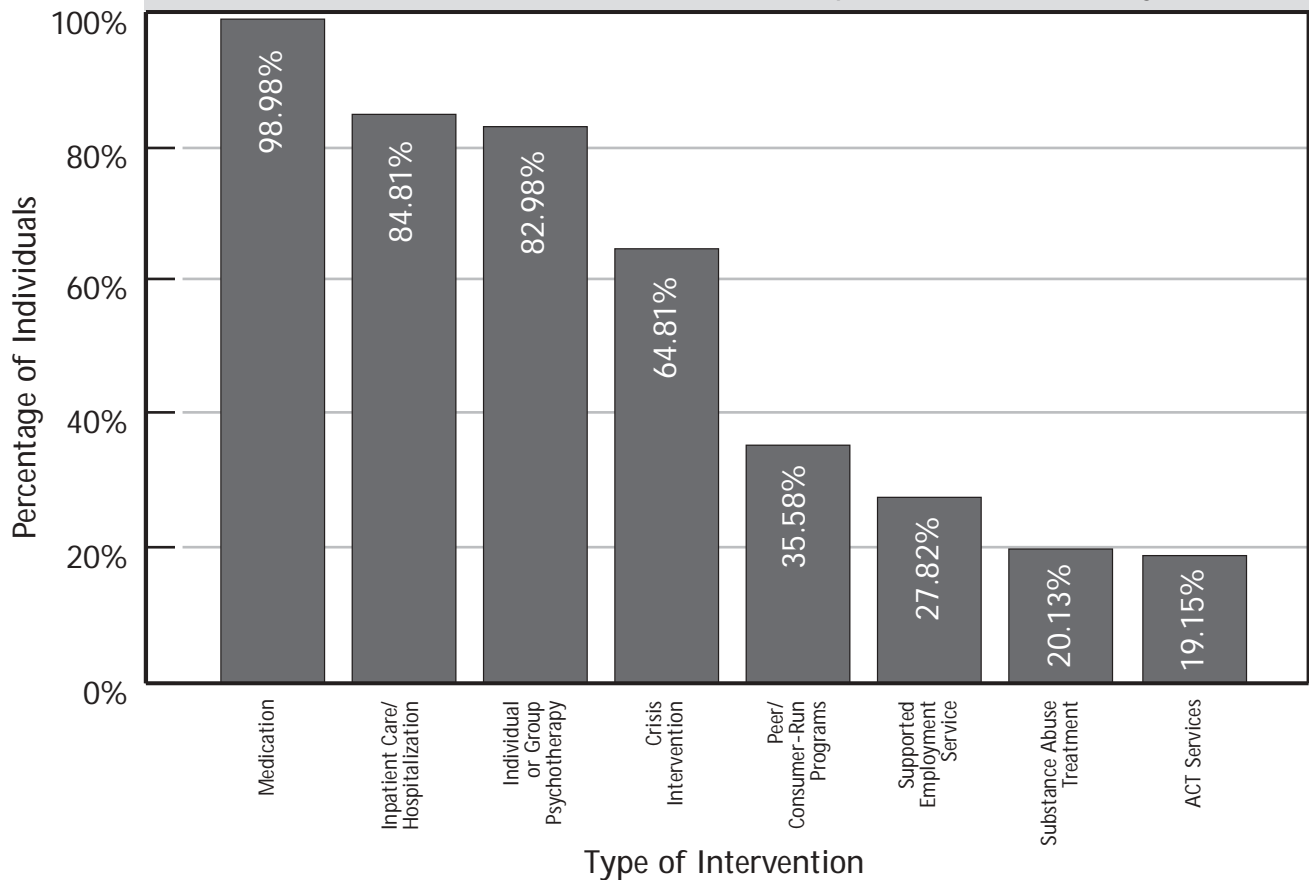
Data on health insurance coverage show that 37 percent of the people with mental illness represented in the survey are covered by Medicare and the same percentage (37 percent) are covered by Medicaid (table 3). The next most frequent forms of health insurance are provided through privately purchased health insurance through an employer (24 percent) or self-paid (13 percent). Most consumers had only one form of health insurance (68 percent), although 32 percent reported multiple coverage, most frequently Medicaid and Medicare (15 percent of those with multiple coverage). Nearly 10 percent of the individuals with mental illness represented in the survey reported no health insurance coverage at all.

**Figure 3.**

**Diagnoses Received by Individuals Represented in the Survey**



**Most individuals in the survey, of the 3,352 total responses to this question, have received a diagnosis of schizophrenia or a major mood disorder.**

**Figure 4.****Interventions for Mental Disorders Ever Received by Individuals with Mental Disorders Represented in the Survey**

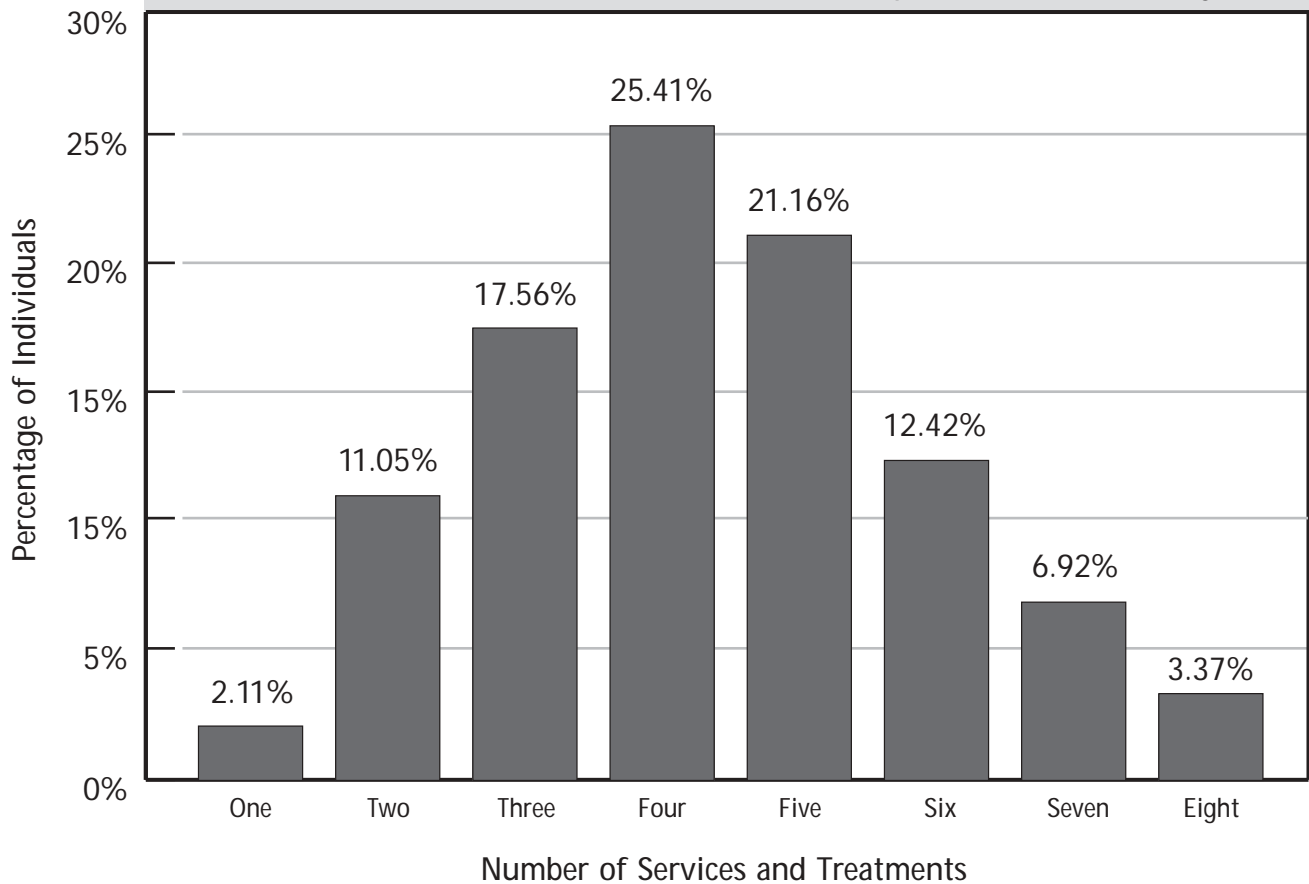
*The vast majority of individuals represented in the survey, based on 3,306 responses, has received medication, hospital care, psychotherapy and crisis services for their mental illness at some time in their lives.*

## Mental Health Diagnoses and Service History

More than half of the individuals with mental illness represented in the survey were diagnosed with schizophrenia—52 percent—at some time during their lifetime (figure 3). Forty-two percent have received a diagnosis of bipolar disorder and 28 percent major depression. Only 12 percent of the individuals had an alcohol abuse disorder diagnosis and 11 percent reported a drug abuse disorder diagnosis. More than half of the individuals with a mental illness—57 percent—have had more than one diagnosis, with 25 percent having two, and 15 percent having three diagnoses. The most common multiple diagnoses were schizophrenia and manic depression/bipolar disorder.

Nearly all of the individuals with mental illness represented in the survey—99 percent—reported receiving medication at some time in their lives (figure 4). The vast majority has also been hospitalized at some time during their lives for their psychiatric illness—85 percent. Eighty-three percent have participated in individual or group psychotherapy at some point. And sixty-five percent received crisis services at some point in their lives, such as admission to an emergency room.

**Figure 5.** Frequency of Multiple Services and Treatments Ever Received by Individuals with Mental Illness Represented in the Survey



***Most individuals represented in the survey received multiple interventions for their mental illness.***

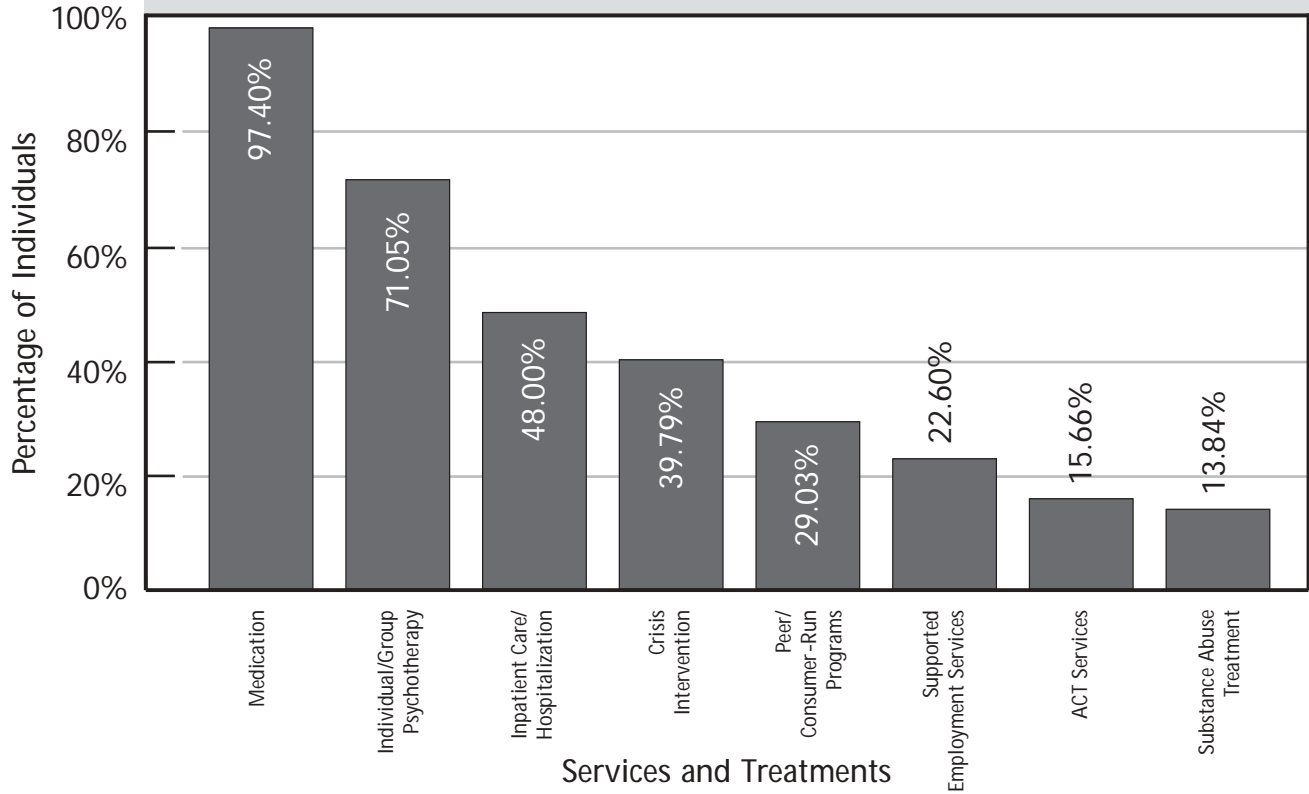
Other services were less frequently accessed by individuals with mental illness during their lives: 36 percent reported ever receiving peer/consumer run programs; 28 percent supported employment services; 20 percent substance abuse treatment; and 19 percent Assertive Community Treatment (ACT).

Most of the individuals represented in the survey accessed multiple interventions, with 69 percent receiving between four and eight interventions in their lifetimes (figure 5). Only two percent had received only one intervention.

A similar pattern of service use was seen in the last year (figure 6). Ninety-seven percent of the individuals received medication for the treatment of their mental health condition. Seventy-one percent received psychotherapy. Nearly half—48 percent—were hospitalized for their mental illness in the last year and 40 percent received crisis intervention services. Again, peer-run programs, supported employment, ACT, and substance abuse treatment were received by a minority of individuals represented in the survey in the last year. Multiple services were the norm as well, with 26 percent of the people with mental illness receiving two interventions in the last year (figure 7), most frequently being medication and psychotherapy.

**Figure 6.**

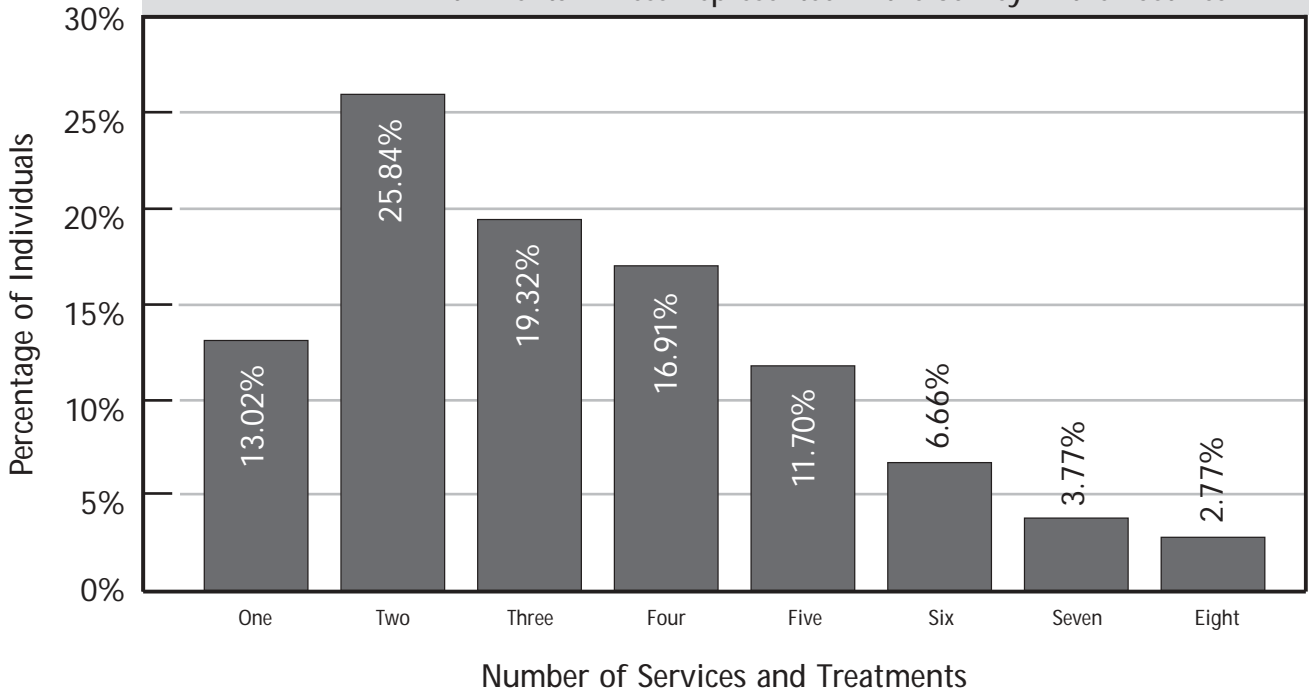
**Mental Health Services and Treatments Received by Individuals with Mental Disorders in the Last Year**



***Nearly half of the total 3,098 individuals reflected in the answer to this survey question were hospitalized for their mental disorder in the last year.***

**Figure 7.**

**Frequency of Multiple Services and Treatments Received by Individuals with Mental Illness Represented in the Survey in the Last Year**

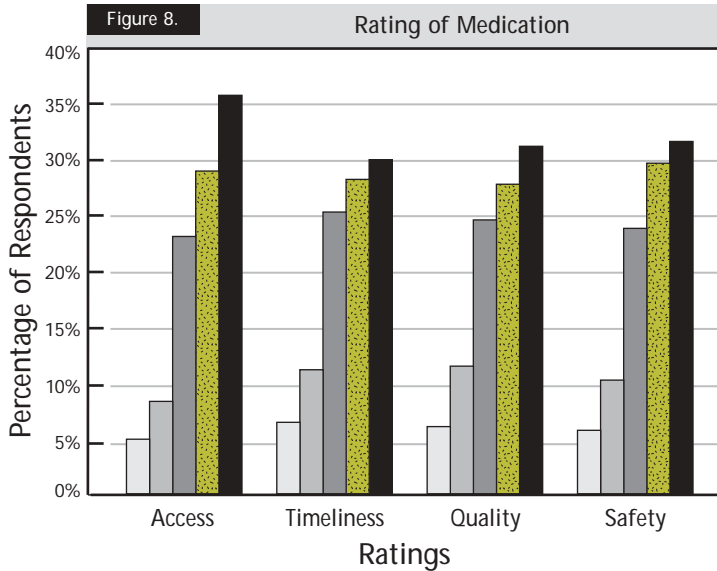


***Most individuals represented in the NAMI survey received at least two interventions for their mental disorder in the last year.***

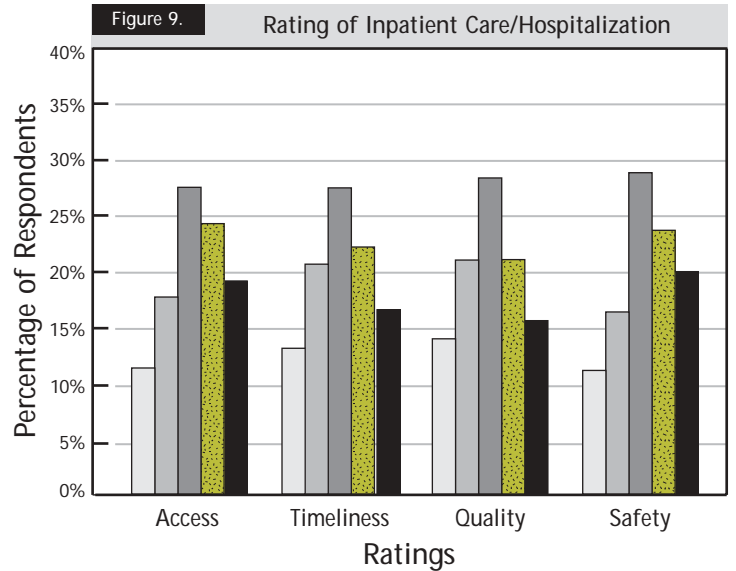


## Figures 8-15: Overall Ratings of Services and Treatments

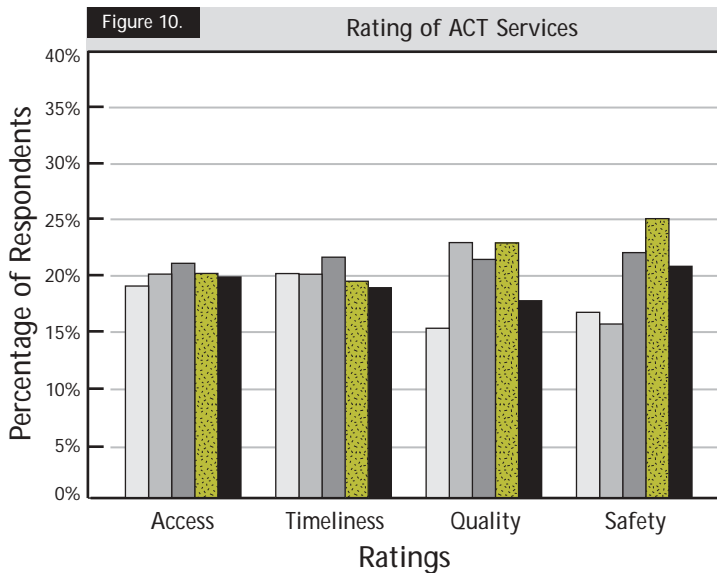
**Figure 8:** The following number of respondents characterized medication treatment received in the last year: 2,990—access; 2,849—timeliness; 2,841—quality; 2,810—safety.



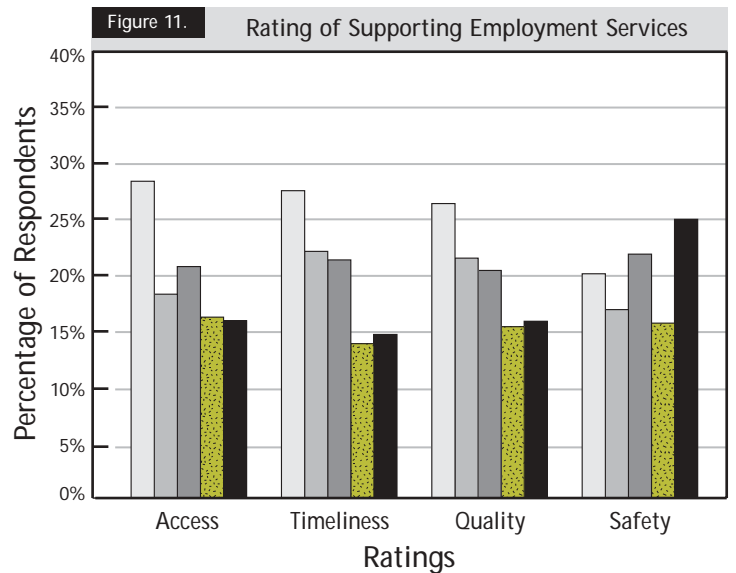
**Figure 9:** The following number of respondents characterized inpatient care received in the last year: 1,441—access; 1,395—timeliness; 1,401—quality; 1,380—safety.



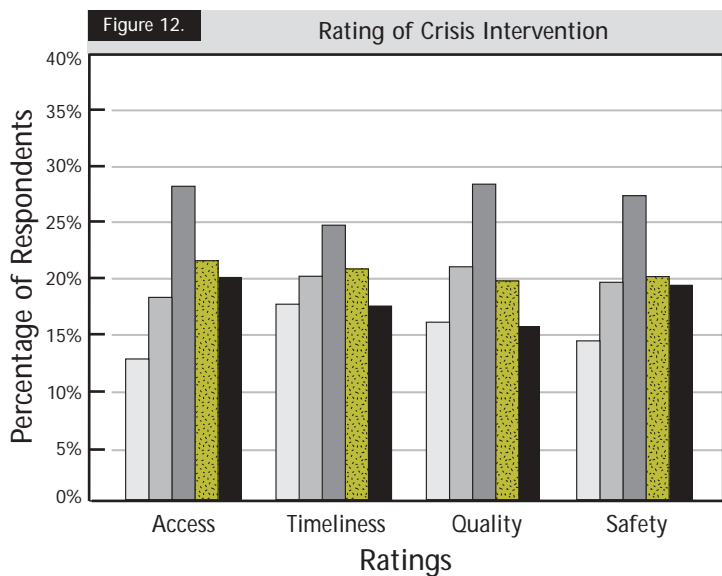
**Figure 10:** The following number of respondents characterized ACT services received in the last year: 485—access; 466—timeliness; 463—quality; 456—safety.



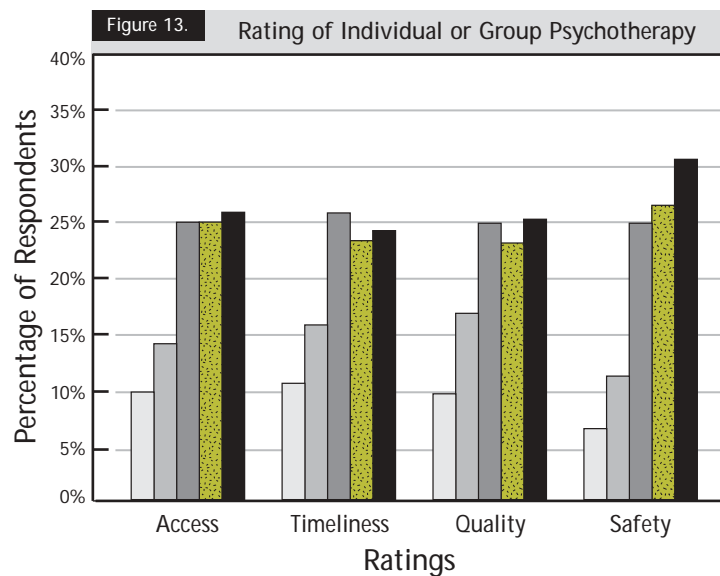
**Figure 11:** The following number of respondents characterized supported employment services received in the last year: 696—access; 643—timeliness; 647—quality; 611—safety.



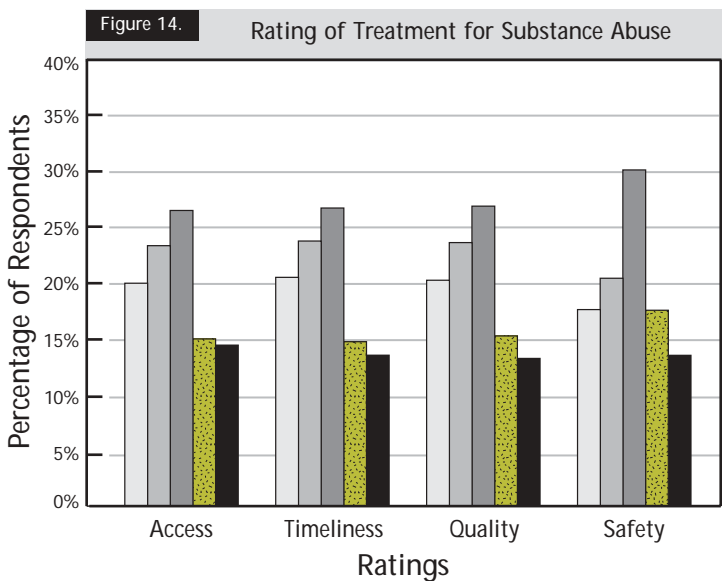
**Figure 12:** The following number of respondents characterized crisis intervention services received in the last year: 1,258—access; 1,205—timeliness; 1,195—quality; 1,187—safety.



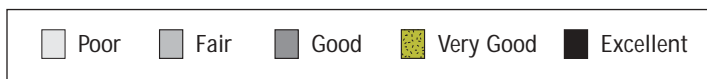
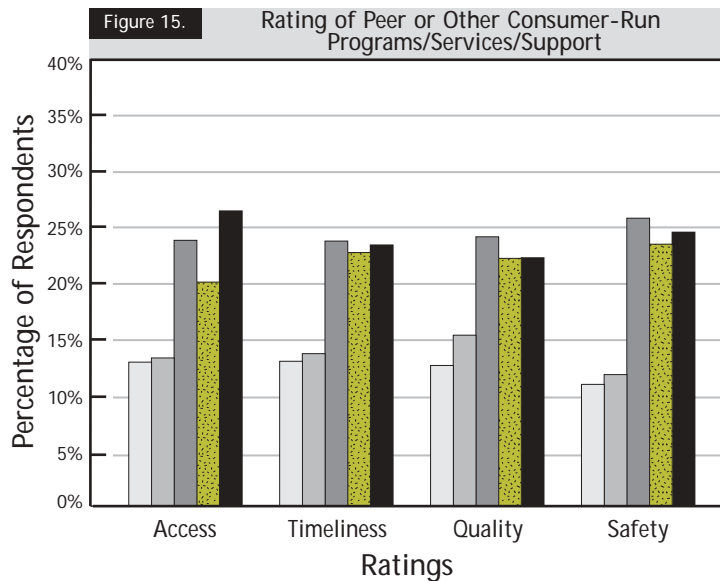
**Figure 13:** The following number of respondents characterized psychotherapy received in the last year: 2,164—access; 2,063—timeliness; 2,062—quality; 2,028—safety.



**Figure 14:** The following number of respondents characterized substance abuse treatment received in the last year: 419—access; 396—timeliness; 399—quality; 389—safety.



**Figure 15:** The following number of respondents characterized consumer-provided services received in the last year: 877—access; 832—timeliness; 826—quality; 822—safety.



## Rating of Mental Health Treatment

Respondents rated access, timeliness, quality, and safety of each mental health intervention received by the individual with a mental illness in the last year as poor, fair, good, very good, or excellent according to the following definitions:

**Access:** Did you or your loved one know where and how to get the service or treatment?

**Timeliness:** Was the service or treatment received in a reasonable amount of time?

**Quality:** Were you or your loved one satisfied that the service or treatment met your expectations and was helpful in meeting your needs?

**Safety:** Did you or your loved one feel confident that the service or treatment did not put you or your family member at risk of harm?

Figures 8 through 15 portray the results for each intervention. Combining ratings of poor/fair and very good/excellent for each rating of each intervention provides a portrait of how different interventions compare (tables 4 through 7).

**Table 4.** Access Rating for Different Interventions Received in the Last Year by Individuals Represented in the Survey

Intervention Type	Percent Rating Intervention Poor or Fair	Percent Rating Intervention Very Good or Excellent
Medications	13.06	64.07
Inpatient Care/Hospitalization	29.03	43.43
ACT	39.05	39.92
Supported Employment	46.90	32.26
Substance Abuse Treatment	43.65	29.64
Crisis Intervention	30.69	41.26
Psychotherapy	23.83	51.09
Consumer Provided Services	27.09	48.23

**Table 5.** Timeliness Rating for Different Interventions Received in the Last Year by Individuals Represented in the Survey

Intervention Type	Percent Rating Intervention Poor or Fair	Percent Rating Intervention Very Good or Excellent
Medications	17.37	57.61
Inpatient Care/Hospitalization	33.75	38.75
ACT	40.16	38.26
Supported Employment	49.91	28.63
Substance Abuse Treatment	44.60	28.48
Crisis Intervention	37.48	37.96
Psychotherapy	26.32	47.75
Consumer Provided Services	27.57	47.81

**Table 6. Quality Rating for Different Interventions Received in the Last Year by Individuals Represented in the Survey**

Intervention Type	Percent Rating Intervention Poor or Fair	Percent Rating Intervention Very Good or Excellent
Medications	17.31	58.37
Inpatient Care/Hospitalization	34.97	36.32
ACT	38.09	40.53
Supported Employment	48.14	31.35
Substance Abuse Treatment	44.24	28.71
Crisis Intervention	36.72	35.05
Psychotherapy	26.42	58.57
Consumer Provided Services	28.90	46.08

**Table 7. Safety Rating for Different Interventions Received in the Last Year by Individuals Represented in the Survey**

Intervention Type	Percent Rating Intervention Poor or Fair	Percent Rating Intervention Very Good or Excellent
Medications	15.74	60.67
Inpatient Care/Hospitalization	27.47	43.67
ACT	32.21	45.80
Supported Employment	37.17	40.86
Substance Abuse Treatment	38.33	31.31
Crisis Intervention	33.66	39.14
Psychotherapy	17.59	57.40
Consumer Provided Services	23.47	49.78

Medication was rated in all domains the highest of all interventions, followed by psychotherapy and consumer-provided services. Medication access, timeliness, quality, and safety were rated very good or excellent by 58 to 64 percent of those responding. Psychotherapy followed, rated very good or excellent in terms of access, timeliness, quality, and safety by 48 to 59 percent of those who received the service in the last year. Consumer-provided services were rated very good or excellent by 46 to 50 percent of those responding.

Supported employment services received the poorest ratings of all interventions for access, timeliness, quality, and safety, with half of the members giving this intervention poor or fair marks in terms of access, timeliness, and quality. More than a quarter of respondents rated it poor in these measures. Substance abuse services followed, with 44 percent of respondents rating the access, timeliness, and quality of this intervention as poor or fair. ACT services were characterized as poor or fair in terms of access, timeliness, and quality by nearly 40 percent of those responding.

## Living Arrangements

The most frequent types of living arrangement for individuals with a mental illness represented in the survey were living alone (31 percent) and living with parents (25 percent) (table 8). Satisfaction with current living arrangement was assessed directly by asking for a rating of satisfaction with current residence or living situation on a scale including *yes, somewhat, no, unsure*. Fifty-five percent of the respondents indicated satisfaction with their living situation.

Despite more than half reporting satisfaction with their living arrangement, more than half of the respondents identified significant barriers to the most appropriate housing (table 9). The most

**Table 8. Living Arrangements of Individuals with Mental Illness Represented in the Survey**

Living Situation	Percent of Individuals (3,301 total responses)
Alone	30.91
With Parents	24.51
With Spouse/Domestic Partner	17.86
In a Supervised Community Residence	9.31
With Friends/Other Adults	4.78
With Other Family Members	3.48
In a Psychiatric Hospital	3.04

**Table 9. Barriers to Housing Reported by Members**

Barriers	Percent of Members Identifying the Barrier (1,776 respondents total)
Housing costs are too expensive	50.05
Lack of community supports for independent living	39.72
More structured care not available	27.75
No financial assistance from government to pay for housing and support	28.33
Appropriate housing is limited due to stigma against people with mental illness	24.63
Family does not support living independently	8.20
Other	18.52
Unsure	8.24

commonly identified barrier to appropriate housing was cost—housing was too expensive. Forty percent cited lack of community supports for independent living. Other commonly cited barriers to appropriate housing included: lack of public assistance for housing (28 percent); the lack of more structured residential care availability (28 percent); and stigma (25 percent).

## Employment

Most individuals with a mental illness represented in the NAMI survey were unemployed—67 percent of the 3,273 respondents to this question. Another 17 percent were employed part-time (less than 35 hours per week). Fourteen percent of the people with a mental illness were employed full-time, 35 hours or more per week. Less than half of those who responded indicated satisfaction with their employment status—44 percent.

Numerous barriers to employment were identified by respondents, including stigma and discrimination against individuals with mental disorders (45 percent) and fear of losing health or disability income benefits (40 percent), (table 10). Other barriers included inadequate treatment of mental health condition (28 percent), lack of vocational services (23 percent), and lack of transportation to job/employment services (20 percent).

**Table 10. Barriers to Employment Reported by Members**

Barriers	Percent of Members Identifying the Barrier (2,585 respondents total)
Stigma and discrimination against people with mental disorders	44.85
Fear of losing health or disability income benefits	39.83
Inadequate treatment of mental health condition	27.68
Lack of vocational services	22.52
Lack of transportation to job/employment services	19.59
Other	31.46
Unsure	7.32

## A NAMI Voice: The High Cost of Stigma and Discrimination in the Workplace

Four years ago, I had a job that I loved, surveying consumer satisfaction in the local mental health care system. A requirement for the job was that the position be filled by a consumer or family member. I am both, and I identified myself as suffering from bipolar disorder, but I noted that I received regular care and had been stable and employed for all my adult life.

I had been successful in my job. Unfortunately, after I disagreed publicly with a regional mental health official about how satisfaction survey contracts were awarded everything began to unravel. The day following that public meeting, my boss called me into her office and claimed that I had embarrassed her and the organization. Furthermore, she asserted that my public comment was a symptom of my illness.

It was not.

When my boss and two county officials confronted me a week later I learned that they had discussed my illness amongst themselves and with others. I soon discovered that my peers had discussed my illness in front of their children and friends. My daughters heard about the "so called symptoms" at their local high school. They were 13 and 17 years old. "Was it true that their mother was crazy and had been fired?" they asked me.

Doors to employment that had been open for me closed quickly. Employers with whom I had good relationships wouldn't return my calls. My letters and resumes were ignored.

Where to turn? I knew of the employment services in my county. I had worked with this agency as a professional in the past. Many of my peers received services in the "workshop environment" provided by the employment agency. They were sent on interviews for jobs bussing tables and fast food restaurant jobs.

I went to the federal vocational program in our area. They tested all of my abilities and determined that I had an above average IQ and superior intelligence. Thus I would not qualify for retraining. However, they offered to place me in an office to answer phones on a part-time basis. Although this outcome would improve their performance statistics, it would disqualify me for SSDI, which I increasingly believed was my only choice.

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.

*Excerpt of comments presented by Donna, NAMI member and consumer advocate, at the NAMI national convention, Minneapolis, MN, June 29, 2003.*

## Criminal Justice System Involvement

Forty-four percent of people represented in the survey, of which 2,585 responded to the question, have been arrested or detained by the criminal justice system over the course of their lifetime. Of those with involvement with the criminal justice

system, only 35 percent reported receiving services that could prevent unnecessary arrest. And only 60 percent reported receiving needed mental health treatment following arrest or detention.

### A NAMI Voice: The Ultimate Cost of Criminal Mistreatment

My son Chuck was 46 years old when he died in October of 2000. His story is one of neglect—no outright, cruel mistreatment by the criminal justice system, from which I was shut out, forbidden from coming to his aid.

Chuck had a long history of health and mental health problems and was under the care of a psychiatrist and receiving several medications for years. He also had a history of drug abuse, which he battled for many years, and ultimately led to his last arrest.

That's when Chuck's final journey started. After I bailed him out of jail, and he hired an attorney, Chuck was found asleep in his car in possession of "a controlled substance" and was jailed in the county jail on October 18th, 2000. His brother, his friends, and I had been trying to find him for several days when I received a letter from the police addressed to him, advising him that they were in possession of his personal items.

We frantically began calling the police department. They did not admit that an arrest had occurred, but referred us to the county jail. I called his attorney to see if he had heard from Chuck and he had not. We called the jail repeatedly and they had no record of his being there. After several days, they finally admitted that he had been there all along. When I went to visit my son on visiting day, I waited all day but was never called. At the end of the visiting period, I asked why. I was told that Chuck was subject to discipline and could not have visitors.

The next day we learned that Chuck was in the hospital and was not expected to survive. The cause of death was determined by the autopsy to be neuroleptic malignant syndrome due to medication given Chuck while he was in jail.

We later learned that when he was initially screened in the jail, he told them about his medications, but none of these drugs were given to Chuck. After several days of trying to get attention to his needs, Chuck attempted to hang himself. When he was discovered, they moved him to the part of the jail used to house the mentally ill. He was never given any of his prescribed drugs. Instead he was put on various other medications. He became more and more irrational, was strapped to a chair. Although Chuck had the classic symptoms of neuroleptic malignant syndrome, he was not given any medical treatment to combat or treat the syndrome nor was he taken off the medicine that caused it.

He died because of total neglect and cruelty with no one to turn to for help.

*Excerpt of comments presented by Jo, NAMI member and family advocate, at the NAMI national convention, Minneapolis, MN, June 29, 2003.*

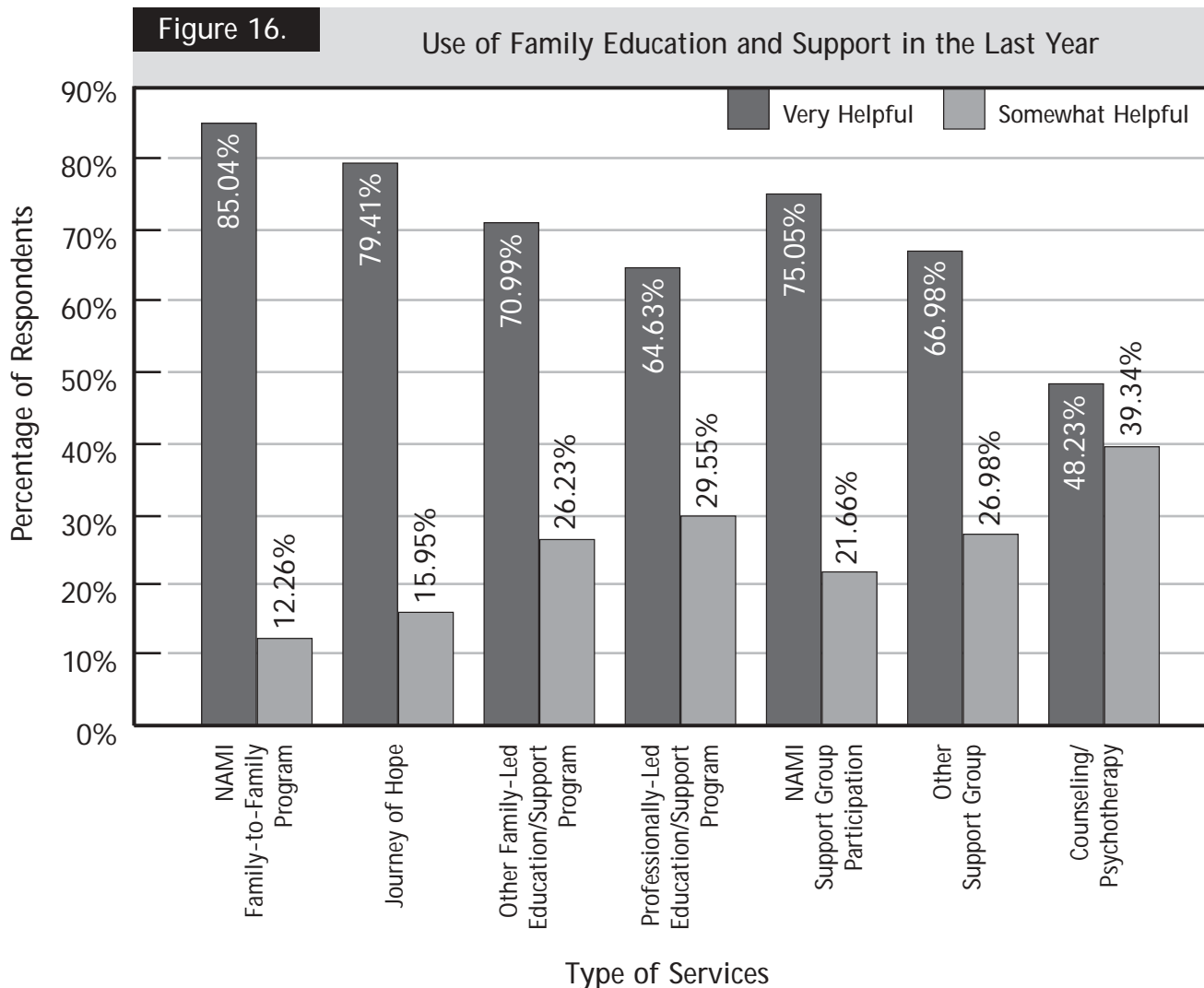
## Co-Morbid Medical Conditions

Twenty-nine percent of the 3,245 individuals reflected in the response to this question reported a serious non-mental health medical condition, with the majority of these, 88 percent, receiving needed treatment for the medical condition. Seven percent reported that they need treatment for the medical condition but cannot get it.

## Family Education and Support

Questions about family education and support services were included in the survey. Just over half of the members, 54 percent, reported access to

family education and support services in the last year. Of these, more than half, 58 percent, had participated in a NAMI support group and 47 percent had participated in the NAMI Family-to-Family program. Other such programs accessed included professionally led education/support programs (17 percent) and counseling or therapy (3.4 percent). In general, members reported that the family education and support programs were helpful (figure 16). The Family-to-Family program was rated very helpful by 85 percent of the members. Professionally led programs were rated very helpful by 65 percent of the members.



**The 3,245 total respondents to this question identified NAMI's Family-to-Family program as one of the most helpful for family members.**



# Discussion

The results of this national study paint a portrait of a disenfranchised group of Americans in the prime of their lives struggling with serious mental illness without the benefit of needed services and supports. Most often, as a result, they find themselves living in poverty, without the hope of employment, subjected to repeated crises and hospitalization. They are dependent on family members and friends for housing, transportation, and basic sustenance. More than half rely on public programs and nearly half have been hospitalized in the past year.

The tragedy of these results is that they are avoidable. With proper treatment and support, many of these individuals can manage their illness and pick up their lives where they left off when illness first struck. However, our results show that the majority of individuals living with mental illness in America do not have access to services and supports that have been shown to promote recovery, independence and productivity. In fact, treatment access in the year 2003 mirrors that reported in a survey of NAMI members more than ten years ago, despite the fact that most of the respondents have been members of NAMI less than five years.<sup>9</sup> Added to this lack of access to services are the unacceptable barriers of stigma and discrimination and the very real fear of losing health insurance and income supports. In short, these results stem from failed public policy, the absence of effective programs and services in most communities, and continuing stigma and discrimination, and, they are largely avoidable.

Of course there are limitations to the data presented in this report. Most importantly perhaps is the fact that this representative sample of NAMI members is not representative of all U.S. citizens living with a severe mental illness. Few persons of Hispanic, African American or other racial/ethnic origins other than white are represented in the sample, although NAMI has engaged in a strong effort to reach out to persons of all races and ethnicity. Co-occurring substance abuse or medical illnesses are relatively uncommon among the respondents, despite evidence that these issues ravage the larger

population of individuals with severe mental illnesses.<sup>10</sup> The data reported here do not reveal distinctions between consumer and family member respondents or those from different geographical regions of the United States, which will be the subject of future reports.

Still, one might reasonably expect that individuals with severe mental illnesses who join a national advocacy organization, or whose families join such an organization, might be better positioned to access effective services and achieve better outcomes. Yet, most of the individuals with mental illness reflected in this survey are experiencing severe poverty, low levels of employment, intense reliance on emergency-based public programs, extensive use of traditional, non-recovery oriented interventions, poor access to community-based services, and widespread involvement in the criminal justice system.

## **Roadblocks to Recovery: Failure to Access Appropriate Medications**

The survey data fail to reveal the full details of a life interrupted by a severe mental illness and the frustrating search for assistance and support. Even though medication was used by virtually all individuals represented in the survey and access and quality of medication was rated highest of all interventions, many reported problems with medication access and quality. Thirteen percent of those using medications rated access as poor or fair; timeliness and quality of medication access were rated poor or fair by 17 percent of the respondents. Safety was rated poor or fair by 16 percent.

The open-ended responses show the frustrations and delays experienced by many individuals with severe mental illnesses in finding medications that work well for them and have manageable side-effects. One survey respondent noted the years-long entrapment given voice to by many who provided open-ended responses:

“Eleven years ago my son was diagnosed at an out-patient clinic with schizophrenia, handed some medication, saw a psychiatrist every eight weeks and a case-worker once a week...I’ve lost count of how many doctors and caseworkers he’s had, or how many different medications he has been given.”

Problems with prescription medication were also described in open-ended comments by the respondents, as well as the costs of such mistakes.

“In February 2002 a mail order prescription ...was incorrectly filled [by a mail order pharmacy service]....One of the prescribed medications was lithium carbonate, 300 mg; they sent lithium carbonate 150 mg instead...My wife was on this reduced strength medication for 41 days before I realized what was wrong...After 22 years of prescriptions always being filled correctly!...This has resulted in three hospitalizations in eight months.”

Another respondent wrote that “[d]ue to poor supervision of obvious signs of medication overdose, hospitalization was necessary. Now, with new and different medications and more frequent doctor visits and blood test, my manic depression is under control.”

The bureaucratic as well as cost barriers to medication access were also described, such as this comment by one respondent:

“The main problem facing our daughter with bipolar illness is the paperwork that has to be completed in order to receive her meds... somehow this past week she was denied one of the meds she had to order and her mother had to write a large check to pay for it. Evidently she was busy with other commitments (part-time employment), and forgot the necessary paperwork. But why do they have to complete this in the first place? She will be taking three meds for her illness probably for life. If I weren’t alive—how would this be paid for? Her income from SSDI and her part time job is not sufficient to cover these costly meds.”

Worries about the cost of medication surfaced in many open-ended responses. One respondent wrote:

“My son is 17 years old and is covered under my health insurance plan...I am very pleased with them, but have great concerns of how he will be able to afford his medication once he is no longer covered by his parents. He takes three medications, the cost, if not covered by the plan, would be over \$1,000 per month.”

Still another wrote: “The high cost of medication—approximately \$500 per month, can no longer be met, due to benefits in Oregon financial cuts. (The parent of this consumer) cannot cover the financial costs.”

Appropriate medication can lead to successful outcomes, if you can find one, as many respondents indicated in their surveys. One respondent wrote:

“Too many patients have to wait a long time to see the doctor even with an appointment. (My son) is not getting psychotherapy currently because there is no therapist at the mental health center. Currently [he] sees the doctor about once every two months or so to get prescription refills. But medication has been good for our son. He has been able to hold a steady job and take college classes at night.”

Appropriate medication is a cornerstone from which recovery often springs for people with serious mental disorders, as many research studies show.<sup>11</sup> Yet at this time, many states are moving to limit access to medications critical for the treatment of severe mental illnesses such as schizophrenia and bipolar disorder.<sup>12</sup> Federal and state policies must be implemented to assure access to effective medications for severe mental illnesses.

## **Lost in the Prime of Life**

From our perspective, one of the most unacceptable results from this survey concerns the chronic unemployment experienced by people with serious mental illnesses. Approximately two-thirds of individuals in our survey were unemployed.

Further, a proven strategy for moving people into employment—supported employment—was unavailable or of poor quality. According to the survey data, supported employment services were received by fewer than one-third of the individuals who needed it and, among those who received the service, access and quality were rated the poorest of all interventions. Obviously the implementation of quality supported employment services is scandalously lacking in the United States, despite the fact that employment support services are often necessary, are extremely effective, and, according to experts, should be offered to virtually all individuals with a severe mental illness.<sup>13</sup>

The survey respondents also identified fear of losing health and income benefits as a major barrier to employment. This situation remains unaddressed despite the promise of “ticket-to-work” legislation and other highly touted initiatives to provide a bridge to employment and personal income without the unacceptable risk of losing life sustaining benefits, such as health insurance. The current situation remains one in which individuals and their families coping with serious psychiatric illnesses are most often better off if they don’t work. To maintain a system of incentives that discourages work and forces dependency is poor public policy and a failure of vision.

One respondent captured the terrible dilemma that people with serious mental illness often face:

“My son has had bipolar disorder since 1996, at the end of his second year in college. After years of no work, numerous credit card debts, living at home, he got SSI. Things have gotten better, but now that he is working part-time, he is concerned that he can barely make it. Our state may reduce benefits in health care too. His medicines are very expensive. He lives in a Section 8 apartment. The costs of insurance and medications concern me. Now that he is trying to get back into society his benefits are being reduced and he is stressing out about this. I pray he can find a better job to make ends meet.”

Another parent writes:

“Of great frustration to us is the lack of appropriate vocational training and supported employment for the mentally ill. In our area a private human services agency provides a vocational training program and some supported employment, but the problem is that everyone receives the same training and are placed in the same jobs with no consideration given to the individualized needs of the client. It’s a ‘one mold fits all’ training program and it is not a surprise that most of these clients fail over and over. I firmly believe that our daughter could maintain competitive employment if the appropriate support system was in place. Reluctantly, she has recently applied for SSDI and we are awaiting their determination of eligibility. In the meantime I am making plans to return to work so we can provide her with financial assistance. This is assistance that without this young woman would be homeless. Indeed much needs to be done to help the mentally ill get and keep employment.”

Despite efforts on the part of policy-makers to amend public health insurance and income replacement programs so as to permit greater access to employment without fear of losing needed health care, the need to further revise and better implement these policies is clear.

Expanding supported employment services, educating employers, and reforming public health insurance and income replacement policies alone will not solve the unemployment crisis for people with severe mental illnesses. Discriminatory policies in private health insurance must be ended as well. As one respondent wrote:

“I feel very fortunate that my current boss knows about my mental illness and accommodates my needs for time away from work when I am not doing well. I have always been well enough to hold a responsible, professional job...I also feel very fortunate that I have health insurance coverage through my employer, as I know that I am considered ‘uninsurable’ for individual policies. Still,

## **A NAMI Voice: Unemployment and Poverty as the Results of Disability Policy**

Until 2 months ago, I had been unemployed and unable to work due to serious mental health problems and some physical problems since 1981. For 21 of those 22 years, I have depended on SSDI and SSI for support, which combined, now provides me \$572 a month, or under \$7,000 a year. I have just finished a part-time, 3 month job as a subcontractor with my County. For this work, last month I received my first paycheck in 15 years.

I know poverty first hand. Living on less than \$600 a month in an affluent County on the East Coast has been extremely challenging. I have had to rely on virtually every program and benefit available, including food stamps, Medicaid, Medicare, a section 8 voucher that pays for the great majority of my rent for my one bedroom apartment in which I have lived independently for the past 15 years, other rental assistance, legal aid, donated dental programs, low-income energy assistance programs—you name it.

Everyday expenses, such as needing dental work, new glasses, replacing worn clothing, replacing broken appliances, etc., are prohibitive, let alone the ever-increasing cost of food, transportation, and housing. My parents have helped me out some, such as buying me a television and computer, and letting me use their car—things I could not possibly afford on my own. With the money from my first paycheck, it was a nice feeling to be able to go and buy some needed dishes for the first time in many years without worrying excessively over their \$30 cost.

I have faced numerous barriers to employment. While I am currently in a supported employment program, they played no role in obtaining the three month contract job. In addition, I know all too well the catch-22 dilemmas of risking losing health coverage in order to work. In fact, I fear I will lose my Medicaid coverage from the contract job, even beyond its 3 month time frame, unless, that is, I am willing to not accumulate any savings beyond the \$2,000 SSI asset limit.

I also face losing SSDI and Medicare if I continue working beyond this, and I do have possible opportunities for continued work, assuming I can get the hard-to-find supports I need to be able to do so.

What should I give up? My recovery? Productive work? Access to mental health treatment? Additional income support that permits me to eat every day and stay in my apartment?

*Excerpt of comments presented by Randy, NAMI member and consumer advocate, at the NAMI national convention, Minneapolis, MN, June 29, 2003.*

because we are a small organization (less than 100 employees) the mental health parity law in our state does not affect us. My insurance only pays my mental health bill (psychiatrist for medication management and therapist as needed) at 50 percent. There is also a limit on visits. I feel this is extremely unfair as many companies have less than 100 employees and we are subjected to this unfair treatment because of our mental illnesses. The drugs I take are very expensive and ... I pay 20 percent of the costs.”

Given that many respondents to this survey indicated that they had private health insurance or found inadequacies of private health insurance coverage a barrier to employment make clear the imperative of insurance parity if we are to achieve maximal productivity for people with severe mental illnesses.

Another issue raised by survey respondents as a leading barrier to employment, as well as housing, is that of stigma and discrimination in the community. While stigma and discrimination are well known as co-travelers with mental illness, the frequent citing of this in the year 2003 as one of the most significant barriers to community living and work demonstrates that public attitudes and behavior remain a formidable barrier to recovery in America. How long will we as a nation permit misperceptions, fears, and illegal discrimination to marginalize and handicap individuals coping with serious psychiatric illnesses? Combating the discrimination against individuals with severe mental illnesses, their families as well as psychiatric service providers stands as a striking imperative of the twenty-first century.

### **The Elusive Bright Lights: Peer Programs for Individuals with Mental Illness and Families**

An innovation witnessed in the mental health system over the last twenty years has been the development of peer-provided services for consumers with severe mental illnesses and their family members. Research has shown that consumer self-help and family led education and support can improve recovery and quality of life, in a cost-effective fashion.<sup>14</sup> Data from

this survey support the value of such interventions. Respondents rated consumer run programs among those with the best quality. One individual wrote that once he

“was made aware of a...clubhouse program, they helped me get part time work. I was also happy to utilize their newsletter...That gave me an outlet to share my poems and artwork. After a few years, I became manager of their consumer-run hotline,...and got a stipend paycheck. In short, I lost about 20 years of my life before the support of (the clubhouse program).”

Family members who received education and support services rated these interventions as very helpful, especially family-led courses and support groups. As one respondent simply wrote: “I took the Family-to-Family education course and it changed my life—I gained peace and lost my anger and guilt.”

Unfortunately, even among members of the largest consumer and family organization focused on severe mental illnesses, access to these programs is woefully inadequate. Only approximately one-third of individuals with mental disorders represented in the survey results received consumer-led services. Barely more than half of the family members reflected in these results received family education or support in the last year. NAMI is working vigorously to expand its peer-provided services, including NAMI-C.A.R.E. Mutual Support Program and Peer-to-Peer for individuals with mental disorders, and the Family-to-Family program for family members. The public mental health system also must contribute to the greater expansion of these programs, supporting the minimal costs required and promoting consumer and family led support and education programs as core services. This investment of tax-payer dollars will amount to the best spent money in the public system, reaping an abundance of returns for individuals with severe mental illnesses and their families as well as considerable savings due to improved productivity and a reduction in crisis services and hospitalization. As the Presidential New Freedom Commission on Mental Health calls for more consumer- and family-centered mental health care, peer-provided services should be a key piece of the implementation of the recommendations.

## The Critical Role of Mental Health Providers

Our emphasis on peer-run services does not mean that individuals with psychiatric illnesses and their families can accomplish recovery entirely on their own. On the contrary, access to a sympathetic, skilled and knowledgeable mental health care professionals—doctors, nurses, psychologists, social workers, and others—was often pointed to as a critical event in moving a person toward recovery. The open-ended remarks reveal that it was often finding the right doctor or therapist that makes all the difference for an individual struggling to cope with a serious psychiatric disorder. One respondent extolled the virtues of one physician:

“We have an excellent psychiatrist. He listens. For the most part, he addresses my daughter’s concerns about medication side-effects. He encourages phone calls from her, and returns them promptly. He is so respectful and encouraging to her. He sends the message that she will achieve her goals...and provides so much hope.”

However, open-ended comments also show that individuals with mental illness and family members may have great difficulty finding a psychiatrist or other mental health care provider or that mental health care providers may not provide appropriate or respectful care (A NAMI Voice: The Long and Frustrating Road to Mental Health Care). One respondent wrote about her daughter: “When she experienced her manic stage which progressed to psychosis, we were not told and kept informed or involved in her treatment plan. She was basically put out on the street again and then arrested due to lack of treatment.” Another family member sadly reports:

“One negative thing that I can never forget is that my husband went to see his therapist because he was having suicidal thoughts...and he told the therapist that he was planning on killing himself. The therapist told him to go ahead. That same night my husband talked me into going to a NAMI support group and he stayed home and took an overdose and almost died.”

## A NAMI Voice: The Long and Frustrating Road to Mental Health Care

It was twenty years ago that I began this journey of mental illness. My family physician admitted me to the psychiatric unit of a hospital and a psychiatrist was appointed to me. The hospital was 100 miles from my home. He did get me stabilized on medication within a few days and I went home to try to find a therapist. There were none in my community.

Over the years, the crises have come more often and more severe. Often it has taken phone calls to every doctor listed in the yellow pages, and following every lead that I could get. I would do this on the days when I felt emotionally strong enough to put myself out on a limb and make those calls. I have private insurance through my husband’s job, but always had to find a doctor who was a provider for that insurance. I have never seen a psychiatrist closer than 60 miles from my home, and often drove 100 miles. With the current insurance company, there are no preferred providers within 200 miles. I am using my family practitioner for medication management, agreeing that if I become unstable, that I will have to make the long drive for medication management. We both agree that this arrangement is not in my best interest, but is the best choice for now.

Both of my now young adult children have gone through extended periods of depression. Finding a professional who was qualified to work with them would take hours and hours of telephone calls. I would have to take my kids out of school and drive 100 miles each way. When a crisis would hit in the evenings, there was no where to take them or no one to call. There was nothing a psychiatrist could do 100 miles away and no way to get a child in crisis to them safely. We would sleep with a troubled child between us to insure that they would not harm themselves during the night—and get help the next day. In Nebraska, if you take a child to the emergency room that is in crisis, you run the risk of the child being taken away from your family and your chances of ever getting them back again is very small. A child with a genetic disorder should not be punished in this way.

*Source: Excerpt of comments presented by Cheryl, NAMI member and peer-specialist, at the NAMI national convention, Minneapolis, MN, June 29, 2003.*

## A System in Shambles

Dr. Hogan, chair of the New Freedom Commission on Mental Health, wrote to the President of the United States on October 29, 2002 that:

“Our review for this interim report leads us to the united belief that America’s mental health service delivery system is in shambles. We have found that the system needs dramatic reform because it is incapable of efficiently delivering and financing effective treatments such as medications, psychotherapies, and other services that have taken decades to develop. Responsibility for these services is scattered among agencies, programs, and levels of government. There are so many programs operating under such different rules that it is often impossible for families and consumers to find the care that they urgently need. The efforts of countless skilled and caring professionals are frustrated by the system’s fragmentation. As a result, too many Americans suffer needless disability, and millions of dollars are spent unproductively in a dysfunctional service system that cannot deliver the treatments that work so well.”

The data from this survey amplify the above stated conclusions. Instead of community-based, recovery oriented interventions shown to work, such as ACT, peer services, or even basic medical care, individuals in this survey face exacerbated illnesses, leading to the need for crisis services, hospitalization, and even incarceration. One respondent wrote:

“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. Other than a single ACT team in the city, there are no home visits to ensure medication compliance to help keep people out of the hospital. Last summer...we discharged 30 people to the community knowing there was no nursing service available to them. It was frightening and very unfair to the consumers.”

In addition to ACT services, dual diagnosis services are also critical, as substance abuse treatment was rated one of the most difficult to access interventions in our survey.

The system often seems to neglect individuals with mental disorders and their families, some times with mortal consequences. One survey respondent wrote

“My 35-year-old son jumped from the 10th floor of an apartment complex after almost 48 hours off all meds, less than 3 days following discharge from the hospital for depression (bipolar). (He) misplaced meds given by the staff and called crisis intervention for replacement. The request was denied. Family and police also requested help getting meds. Request denied. We were all told by crisis workers that the patient did not need meds, needed ‘consequence’ of misplacing meds.... Request for doctor on call denied. ‘Wait for regular drop off of meds in 48 hours. We don’t feel like bothering the on-call doctor’ (9 p.m. Saturday). Requests repeated at 3 a.m. Sunday. Suicide at 7:45 a.m. Sunday... My son would not go voluntarily to the ER for meds as he believed he would be sent to the state hospital.”

Hospital and crisis services, while achieving fairly strong accessibility and quality ratings by the respondents in our survey, are not a subject about which to be sanguine. Approximately one-third of the respondents rated the quality and access of these services as poor or fair. The open-ended comments provided chilling stories as well. One respondent told of a 12 hour wait in an emergency room. Another individual wrote of being ridiculed and ignored by psychiatric hospital staff when requesting treatment for her insulin-dependent diabetes. A parent reported terrible delays in seeking crisis care: “During the past year we had a crisis, the first in a few years. The mental health center where we see the psychiatrist...told us we couldn’t talk to a doctor, nurse or employee. The doctor didn’t recognize our consumer’s condition and gave out wrong information that the crisis team couldn’t see anyone at night.” Another survey respondent told of horrible treatment in a psychiatric hospital for their son:

“In one of his hospitalizations...the ward he was admitted to had a policy of removing all the new admissions from their medication. The result was that our son became a ‘zombie.’ It was almost impossible to communicate with him. He paced the floor all day long and rubbed the skin off the back of his foot causing it to ooze. We had to call the staff’s attention to it because they

had not noticed the condition of his feet.”

Housing is another terrible worry for many respondents. One wrote: “My biggest problem is housing. I don’t know what will happen to my son after I die. There isn’t any permanent housing for him in my community.” Another respondent related: “To get into housing, we were told up to a 7 year wait.”

### **A NAMI Voice: The Impossibility of Recovery without Housing**

I am a third generation Mexican American. I grew up with my mother and extended family and never knew my father. My mother was a teenager with undiagnosed mental illness. Mine is a family history of mental illness and alcoholism that has gone on for generations unchecked.

The first time I was homeless I was seven years old. Most of my childhood we spent moving from house to house, from family member to family member. At one time we lived in a van in California, and my three baby sisters and I lived off of food banks. When we lived in another part of California, we had run out of food and had been living off of potatoes for months. One day, my sister was crying in the front yard and a neighbor asked her what was wrong. When she found out that we did not have any food she bought us some. From then on she would drop in and always have something for us to eat in hand. While growing up, at best we lived in substandard housing in very dangerous neighborhoods with gangs, drugs and prostitution all around us.

I didn't know it back then, but I too have a mental illness; I am diagnosed with bipolar disorder and post-traumatic stress disorder. After a tremendously challenging childhood and adolescence, my early adulthood did not fare much better. I continued to have difficulties finding stable housing, which became harder to deal with when I married and had three children.

We attempted to live off a meager existence of \$670 a month. But we couldn't find stable housing. The local housing authority had a five year wait list. To stay off the street, we lived with various family and friends, sometimes renting a room in their home. We applied for every assistance program we could find, but found ourselves caught in a frustrating loop. I was denied low-rent Section Eight housing because my credit was bad, the result of my undiagnosed and untreated illness. No one wanted to rent to us because I did not have a stable work history, or bank account, or references. But when you don't have an address or phone number, you can't give a contact number for jobs. In addition, it also makes it difficult for clinics to make an appointment with you. Throughout this frustrating process, my family and I lived in dangerous neighborhoods where it was not uncommon to hear the crackling and pop of assault rifles on a regular basis. One of the hardest things I faced was having to teach my children to fall flat to the floor when gun shots rang out in the neighborhood.

Thankfully we finally qualified for assistance from the county. We were then able to rent a studio apartment and everything turned around. Once I was able to manage my illness and have some stability in my life, I began to volunteer at a local homeless outreach clinic so I could give back to others who were going through what I had. This has been extremely gratifying for me, especially since I speak Spanish and can help bridge the language and cultural gap that makes getting help so difficult for many people.

*Excerpt of comments presented by Ramiro Guevara, consumer advocate and new national project director of In Our Own Voice, at the NAMI national convention, Minneapolis, MN, June 29, 2003.*



But sometimes mental illness won't wait. Enter the criminal justice system. Nearly one-half of the individuals with mental illness represented in this survey had been arrested or detained during their lives, nearly one third in the last year. While the police can be very helpful during a psychiatric crisis as the data from this survey show and as one respondent wrote: "our local police called me to tell me that they had taken my spouse to the emergency room instead of arresting him"—oftentimes treatment at the hands of the police, jails, and prisons is humiliating and life-threatening. One individual reported that "when I was incarcerated, it took 8 months before I got medication." Another individual recounted that

"the most difficult time for us was two years ago when we were told after the fact that our daughter was being committed by her doctor to the (state psychiatric hospital). She was committed because the hospital was full and her doctor told her that being committed was the only way she could get a bed. Our daughter agreed because she wanted help. Much to her surprise, she was cuffed, put behind the iron screen in the back of the sheriff's car, and transported to the hospital. This whole procedure was very demeaning because we are a family who doesn't even get parking tickets."

Another respondent conjured a dreadful image of the treatment of people with mental illnesses in jail.

"The jail system here is really bad. They do not give people their meds. I know people in jail right now who need their psychiatric meds and can't get them. 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. The medical staff told one inmate 'You're here to be punished, not to be babied.' Another inmate's family member traveled approximately one and a half hours...to bring his daughter's psychotropic medications. After he got there the medical staff person told him she wouldn't be allowed to have them...He told her that this medicine was a matter of life

and death for his daughter and she had been on them for over 20 years. And that the federal ATF guy had called him and requested that he bring them to her at the jail...The staff member told the family member that it was not a matter of life or death as she had been without them since Friday and this was Monday and she could wait another day."

## Ending the National Disgrace

The recent landmark report from the Institute of Medicine (IOM)—"Crossing the Quality Chasm"<sup>15</sup> opens with the assertion:

"The U.S. health care delivery system does not provide consistent, high quality medical care to all people. Americans should be able to count on receiving care that meets their needs and is based on the best scientific knowledge—yet there is strong evidence that this frequently is not the case. Health care harms patients too frequently and routinely fails to deliver its potential benefits. Indeed, between the health care that we now have and the health care that we could have lies not just a gap, but a chasm..."

The data from this survey vividly depict the enormous quality chasm that more than fifteen million Americans living with serious mental illnesses and their families face today. Indeed, the mental health system is not only in shambles, it is a national disgrace. In recent research conducted by the World Health Organization, individuals with mental illness in the United States had less access to mental health services and received services significantly later in their illness than in any other industrialized country in the study.<sup>16</sup> This is a disgrace that the American public needs to know about and which can no longer be tolerated.

### **Step One: Consumer and Family Centered Care**

The IOM report's redesign plan for the health care system centers around the health care consumer. Such a focus is essential for radically reforming the mental health care system into a recovery-oriented,

quality system as well. Individuals with serious mental illnesses and their families must be at the center of treatment decisions, information flow, and control. It is their needs and their choices that should drive the system, that should be anticipated, that drive continuity of care and that, ultimately, create a 'marketplace' of services from which to choose. Consumer-centered care values the desired outcomes of the individual with a mental illness.

The implementation of this step requires a revolution in the way care is delivered, providers are trained, and processes and outcomes are monitored. It means building a mental health system from the ground up and tying funding to the individual, not the program. It also will create a true marketplace of services in which, we believe based on data in this national survey, peer-provided services would thrive. Peer-provided services include consumer-provided services, education, and support and family-provided education and support. The value of these services, in terms of satisfaction expressed by individuals with mental disorders and family members, along with the growing evidence of improved outcomes and cost-effectiveness, demand not only increased research attention, but also widespread expansion.

- NAMI calls on SAMHSA—the Substance Abuse and Mental Health Services Administration—along with each state mental health authority to enact measures that will expand peer-provided services to all individuals with serious mental disorders and their families who need and request them, in the next five years, reporting on implementation progress annually.
- NAMI calls on the National Institute of Mental Health (NIMH) and SAMHSA to study the impact of peer-provided services, documenting the evolving forms, efficacy, effectiveness, cost-effectiveness, outcomes, and best methods for implementation.

### ***Step Two: Applying the Evidence***

The IOM report observes that the needed health care system revolution requires systemic changes, beginning with a wholesale reform of the way evidence-based interventions reach the patient.

Given that the large majority of individuals in our survey were unable to find or access evidence-based practices and interventions, as well as their reports that the limited number of such programs that are available are of questionable quality, this is an area in need of urgent attention.

- NAMI calls on each state mental health authority to develop a five year plan to significantly expand the availability of evidence-based practices, including: appropriate medication and psychotherapy, Assertive Community Treatment (ACT), supported employment services, dual diagnosis services, supported housing, and jail diversion programs; and to report annually, to the public, on the implementation of the plan, including data showing expenditures and number of individuals receiving these services.
- NAMI urges SAMHSA to develop consumer guides to services in mental health showing evidence for effectiveness, and lack thereof, for all services paid for by tax dollars and reported by the states.
- NAMI urges continued and enhanced efforts on the part of federal agencies, provider organizations, academic institutions, and advocacy organizations to effectively disseminate evidence-based interventions for individuals with serious mental illnesses.
- As called for in the “Bridging Science and Service” report of the National Advisory Mental Health Council,<sup>17</sup> NAMI calls for the NIMH to increase its efforts to demonstrate the effectiveness of interventions for serious mental illnesses, to take a lead role in guiding effective dissemination of interventions shown to produce positive outcomes, and to garner feedback from the field as to emergent practices that should be tested for effectiveness. This should be accomplished through an ongoing commitment to research and funding initiatives in this area; the support of large, clinical trials that monitor the implementation of interventions in the real world; regular and real input to the NIMH research agenda from individuals with

mental disorders, their families, providers, and system funders and administrators; and, collaboration with SAMHSA in supporting research and dissemination activities.

- NAMI calls for an Institute of Medicine study on the effectiveness and quality of mental health care providers, including a review of training, licensing and other credentialing mechanisms, geographic distribution, and reimbursement, and to recommend ways in which mental health provider quality can be improved so as to effect not only evidence-based interventions, but high quality, continuous care.

### **Step Three: Funding**

While this survey did not examine the issue of funding, grave questions exist about the adequacy of current investments in the mental health system, given the current budget crises and static or decreasing investments in mental health care.<sup>18</sup> Questions also exist around the use of current funds for evidence-based, recovery-oriented care and supports. The IOM report noted that financing of health care must be aligned with quality improvement. Certainly, the U.S. tax-payer deserves to know whether federal, state, county, and local resources are being spent appropriately. And all of us who want to see our society end the disgraceful mistreatment of individuals with mental illnesses need to know how much it will cost.

- NAMI calls on the major payers for mental health services, including Medicaid, Medicare, state governments, and employers, to develop and implement payment strategies that support the implementation of evidence-based, recovery oriented services for individuals with severe mental illnesses and their families. SAMHSA should monitor these efforts and report annually on the level of investment in these interventions and mechanisms that positively affect appropriate funding.
- NAMI urges NIMH to commission a study that probes the costs of mental illness to society and the current funding of the public mental health system. The aim of this study is to determine the true economic costs including the costs of lost

productivity, income supports and all services in and out of the mental health system and to determine the adequacy and appropriateness of expenditures for services for individuals with serious mental illnesses.

- NAMI calls for an end to state efforts to target budget reductions for interventions that are essential to the safety and health of individuals with serious mental illnesses, such as severe formulary restrictions and reductions in evidence-based services such as supported employment, substance abuse treatment, ACT programs, and others.

### **Step Four: Ending the Barriers to Recovery**

The individuals who responded to this survey gave voice to many barriers to appropriate care and recovery, especially employment and housing. Many of the barriers have to do with public policies that serve as powerful disincentives to employment, such as the requirements of the disability income programs, ongoing access to public sources of health insurance, and the lack of coverage of mental illness treatment in private insurance. Despite efforts to reduce these barriers, their pernicious impact persists.

The diffuse and unfocused responsibility for the public mental health system in each state also serves to erect barriers to optimal employment services, housing, and jail diversion services. Accountability to individuals with mental illnesses and their families as well as the public is also severely compromised. The IOM report noted the enormous barriers that exist in large, complex health care systems, which must be addressed if we are to cross the quality chasm.

Public policy and its implementation are not the only unacceptable barriers to employment and recovery. The ongoing stigma and discrimination still experienced by individuals with mental illnesses and their families can no longer be accepted.

We should also note that people of color or from different ethnic or cultural groups often experience much larger barriers to recovery, by virtue not only of a mental illness, but also because of discrimination, poverty, and the lack of culturally appropriate

services.<sup>19</sup> The mountain that they have to climb to recovery is often far greater due to these barriers, and they too must be eliminated if we are to have an equitable mental health care system, which is a cornerstone of quality as noted in the IOM report.

- NAMI urges the U.S. Congress to hold a series of hearings on persisting barriers to employment for individuals with serious mental illnesses, and to propose measures that will eliminate such barriers in SSI/SSDI, Medicaid, Medicare, and other programs and policies.
- NAMI urges the passage of federal legislation that ends discrimination against people with mental illnesses in health insurance.
- NAMI calls on the U.S. Department of Justice and other appropriate federal agencies to clamp down using the full force of law to punish those who illegally discriminate against people with mental illness in housing, employment, and access to community services.
- NAMI calls on each state to report on services and outcomes among individuals from various racial and ethnic groups and to expand services and supports systematically to eradicate inequitable access and outcomes in the next five years.

#### ***Step Five: Public Accountability and Information Technology***

The IOM report lamented the extreme limits of information technology application to the health care field, even as it has radically transformed virtually every other sector of our culture. The mental health system, if anything, is even more out of sync with the kinds of technology that can enhance patient safety, improve continuity of care, permit system performance monitoring, and give individuals with mental illnesses, their families, and providers usable information so as to improve decision-making and outcomes. While issues of confidentiality offer challenges, a twenty-first century mental health system is not possible without the full power of twenty-first century technology.

We see the development and implementation of sophisticated information technology systems as

central to accountability of the mental health system. All of the tax-paying public should be able to easily discern the amount and uses of public funds in the mental health system—what kinds of services, how many individuals served, expenditures per service and per individual. The information should go beyond mental health services, also including information about housing services and costs, vocational rehabilitation, incarceration, and emergency room use. Outcomes for individuals with mental illnesses must also be tracked—meaningful outcomes that go beyond symptoms and include employment and housing stability, for example. In this way, we will be able to understand what public funding is really buying.

As the IOM report notes, large-scale investments in infrastructure and technology will be required for such reforms to be enacted, as well as behavioral changes on the part of administrators and providers—all requiring a multi-year investment. Still, without the investment, the public mental health system will not be held accountable to individuals with mental illnesses, their families, and the tax-paying public.

- Building on the work of the Presidents' New Freedom Commission on Mental Health, NAMI calls on the U.S. Department of Health and Human Services to immediately develop a plan to significantly improve information technology use in the public mental health system—including state and local agencies funding and/or administering services for individuals with serious mental illnesses and provider organizations—with the input of all relevant stake-holders and including a time-line and budget, so that the public investment in mental health care can be readily discerned by the tax-paying public and its representatives.

#### ***Step Six: A Role for All of Us***

“Crossing the Quality Chasm” notes that to see significant improvements, all of the stake-holders in the health care system must be engaged in the enormous task of reform. So too it is for the needed reform of the mental health system. The sheer magnitude of the effort needed to create, from the tragic shambles the mental health system is today, a

high quality, recovery-oriented, accountable system of care requires a strong coalition of advocates, providers, and policy-makers.

All of the recommendations above will require the strong voice of stake-holders in the mental health system, either in providing input into investigations, studies, and planning activities, or as advocates for the implementation of the policy changes. This input and advocacy will be necessary at the federal and state level. We, in the mental health community, will have to work together more powerfully than ever before if the disgraceful treatment of people with mental illnesses is to end any time soon. Our challenge is to raise all of our voices together, so that we cannot be ignored by policy-makers who would continue to close their eyes to the tragedy that we as individuals with mental illnesses, family members, advocates, friends, and providers cannot ignore.

We must also work continuously to educate the public about mental illnesses—dispelling the ignorance and prejudice that persists and conveying information about effective and appropriate treatment. The latter is important not just to build support for investment in effective treatment, but also so that any individual or family who comes to find themselves facing the onset of a mental illness will act promptly and without fear to gain access to interventions that work.

Providers of services in the mental health system have an obligation to reform their own behavior, making sure that the care being delivered is safe, of high quality, in line with the best scientific evidence, and patient- and family-centered. Similarly, consumers of mental health services and their families must demand the optimal care that will lead to recovery.

NAMI has several initiatives underway to address the needs for consumer- and family-provided services, public education, monitoring of system performance, and advocacy. We invite the support and participation of all Americans who care about provoking a true revolution in the mental health system to join us in these efforts.

- **Consumer- and Family-Provided Education and Support:** NAMI has several programs for supporting individuals with mental disorders in their journey toward recovery, including Peer-to-Peer, NAMI C.A.R.E., and In Our Own Voice. NAMI also has a powerful program of education and support for families—the Family-to-Family program. We are working vigorously to expand access to these offerings around the nation.
- **Campaign for the Mind of America:** NAMI's Campaign for the Mind of America is a multi-year effort on many fronts to promote investment in recovery and to prevent the abandonment of yet another generation of Americans with mental illnesses to neglect and hopelessness. The Campaign highlights the need to build a comprehensive, efficient system to screen, evaluate, diagnose and treat mental illnesses at every stage of life.
- **TRIAD: Treatment/Recovery Information and Advocacy Database:** This report is a result of the TRIAD project which will monitor the mental health system in each state and publicly report on trends and outcomes to promote public accountability.
- **Grassroots Advocacy:** NAMI is expanding its grassroots advocacy so as to work more strongly with all who care about the mental health system at the state and federal level. We invite all who are interested in advocacy or any of NAMI's efforts to go to the new NAMI website—<http://www.nami.org>—and learn more about how you can become a part of this effort.



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## APPENDIX A

# TRIAD Advisory Group

*Ken Duckworth, M.D., Advisory Group Chair*

Advisory Group Member	Organization
Neal Adams, M.D., M.P.H. President	American College of Mental Health Administrators
David Almeida Executive Director	NAMI South Carolina
Paul Appelbaum, M.D. Department of Psychiatry A.F. Zeleznik Distinguished Professor and Chair	University of Massachusetts Medical School
Larry Belcher, M.A. CEO/Director	West Virginia Mental Health Consumers' Association/Consumer Organization, National Technical Assistance Center
Bob Bernstein, Ph.D. Executive Director	Bazelon Center for Mental Health Law
Thom Bornemann, Ed.D. Director	The Carter Center Mental Health Program
Jeffrey A. Buck, Ph.D. Associate Director for Organization and Financing	The Center for Mental Health Services, Substance Abuse and Mental Health Services Administration
Jean Campbell, Ph.D. Director, Program in Consumer Studies & Training	Missouri Institute of Mental Health
José Cañive, M.D. Director of Clinical Psychiatry Research	New Mexico Veterans Affairs Health Care System
Patrick Corrigan, Psy.D. Professor of Psychiatry and Executive Director	University of Chicago, Center for Psychiatric Rehabilitation
Mark Covall Executive Director	National Association of Psychiatric Health Systems
Betty Dahlquist, M.S.W., C.P.R.P. Public Policy Chair Executive Director	International Association of Psychosocial Rehabilitative Services  California Association of Social Rehabilitation Agencies
Curtis Decker Executive Director	National Association of Protection and Advocacy Systems, Inc.
Max Dine, M.D. Former Chair, Consumer Council Restraint and Seclusion Committee	NAMI
Robert E. Drake, M.D., Ph.D. Director	New Hampshire-Dartmouth Psychiatric Research Center, Dartmouth University
Ken Duckworth, M.D. Medical Director	NAMI

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Robert Egnew, Ph.D. Director of Government Relations	National Association of County Behavioral Health Directors
Steve Feinstein, Ph.D. President	NAMI Kansas
Pamela Greenberg, M.P.P. Executive Director	American Managed Behavioral Healthcare Association
Tim Harlan Partner	Former Representative, Missouri House of Representatives, Harlan, Harlan, & Still Law Offices
Richard H. Hunter, Ph.D. Clinical and Consulting Psychologist	Clinical Outcomes Group, Inc.
William Lawson, M.D., Ph.D. Chair of Psychiatry Department	Howard University Hospital
Tom Leibfried, M.P.A. Program Director	National Mental Health Consumers' Self-Help Clearinghouse
Ron Manderscheid, Ph.D. Chief, Survey and Analysis Branch	The Center for Mental Health Services, Substance Abuse and Mental Health Services Administration
David Mechanic, Ph.D. Director	Rutgers University Institute for Health, Health Care Policy and Aging Research
Ann O'Hara Associate Director	Technical Assistance Collaborative Inc.
Margaret Pennington, M.S.W. Commissioner Ex-Officio	Kentucky Department of Mental Health and Services Mental Retardation National Association of State Mental Health Program Directors
Marty Raaymakers Chair, Consumer Council Executive Committee	NAMI
Charles Ray President and CEO	National Council for Community Behavioral Healthcare
Philip Renner, M.B.A. Director, Measures Development	National Committee for Quality Assurance
Robert Rosenheck, M.D. Professor of Psychiatry	Yale University Medical School
Donald Sawyer, Ph.D. President	National Association for Rural Mental Health
Steven S. Sharfstein, M.D. President and CEO	The Sheppard Pratt Health System
Donald Shumway President	Crotched Mountain Foundation
Henry Steadman, Ph.D. President	Policy Research Associates, Inc.
Roscoe Swann National Board of Directors	NAMI
Eileen White Consumer Council Executive Committee	NAMI

## APPENDIX B

### 2003 Survey of Consumer/Family Views of Mental Health Services

If possible, please complete this survey online at [www.namisurvey.info](http://www.namisurvey.info). Use the survey ID number found in the lower right corner of this page to access the online survey. If you complete the online survey, you may discard this paper survey.

**Please complete and return this survey by March 21, 2003.**

**INSTRUCTIONS:** Answer each question by circling the number alongside the response that corresponds to your experiences. If you need help completing the survey, please contact NAMI at 800-481-(NAMI) 6264 or by email at [lhall@nami.org](mailto:lhall@nami.org).

1. How would you describe yourself? (*Circle one response.*)
  - 1 A consumer (or person with a serious mental disorder)
  - 2 The family member of a person with a serious mental disorder. → (*Circle only one.*)
    - 1 Parent 2 Spouse/Partner 3 Brother/Sister 4 Son/Daughter
    - 5 Other (*Please specify*): \_\_\_\_\_
  - 3 Both a consumer and family member of a person with a serious mental disorder
  - 4 The family member of a consumer deceased **on or after** January 1, 2002
  - 5 The family member of a consumer deceased **prior** to January 1, 2002 (*Go to Questions 14-24*)
  - 6 A friend or caregiver of a person with a serious mental disorder

If you are a *consumer*, please answer the following questions as they pertain to **you**. If you are the *family member or a friend of a person with a serious mental disorder*, answer the questions as they pertain to him or her. If you are both a consumer and family member, please answer the questions as they pertain to you as a consumer.

2. In what state do you or your loved one with a serious mental disorder **currently** receive mental health services? For example: California, Illinois, Georgia, New York, Maine.

Name of the state: (*Please print.*) \_\_\_\_\_

Confidentiality Pledge: We promise that your responses will be kept strictly confidential.  
Individuals completing the survey will NOT be revealed or identified.

3. Please circle the number next to each of the mental health diagnoses you or your loved one has received.

1 Schizophrenia (including schizoaffective disorder)	8 Attention deficit/hyperactivity disorder
2 Paranoid or delusional disorder (other than schizophrenia)	9 Obsessive compulsive disorder
3 Manic episodes or manic depression (also called bipolar disorder)	10 Mental retardation
4 Major depression	11 Panic disorder
5 Antisocial personality, borderline personality or any other severe personality disorder	12 Other anxiety disorder
6 Alcohol abuse disorder	13 Anorexia, bulimia or other eating disorder
7 Drug abuse disorder	14 Any other mental or emotional disorder ( <i>Please Specify: _____</i> )

4. Circle the number next to each service and treatment that you or your loved one with a serious mental disorder has **ever** received.

- 1 Medication
- 2 Inpatient care/ hospitalization
- 3 ACT services (Assertive Community Treatment services, also known as PACT—Program of Assertive Community Treatment—or intensive case management provided by a team of providers 24 hours a day, 7 days a week, as needed)
- 4 Supported employment services
- 5 Crisis intervention (such as going to an emergency room or crisis intervention clinic)
- 6 Individual or group psychotherapy
- 7 Treatment of substance abuse problem
- 8 Peer or other consumer-run programs/services/support (such as drop-in center or peer-provided job coaching)

5. This question asks about services and treatments received **in the last year**. Circle the number next to each service and treatment that you or your loved one with a serious mental disorder has used. Please rate the services and treatments that were used according to the following:

- **Access:** Did you or your loved one know where and how to get the service or treatment?
- **Timeliness:** Was the service or treatment received in a reasonable amount of time?
- **Quality:** Were you or your loved one satisfied that the service or treatment met your expectations and was helpful in meeting your needs?
- **Safety:** Did you or your loved one feel confident that the service or treatment did not put you or your family member at risk of harm?

Circle the number next to each service and treatment received <b>in the last year</b> .	Please rate <b>each service and treatment received</b> on a scale of 1 to 5, with 1 being poor and 5 being excellent.	Poor	Fair	Good	Very Good	Excellent
		<i>Circle one rating number per line.</i>				
<b>1 Medication</b>	Access was...	1	2	3	4	5
	Timeliness was...	1	2	3	4	5
	Quality was...	1	2	3	4	5
	Safety was...	1	2	3	4	5
<b>2 Inpatient care/ hospitalization</b>	Access was...	1	2	3	4	5
	Timeliness was...	1	2	3	4	5
	Quality was...	1	2	3	4	5
	Safety was...	1	2	3	4	5
<b>3 ACT services—PACT</b>	Access was...	1	2	3	4	5
	Timeliness was...	1	2	3	4	5
	Quality was...	1	2	3	4	5
	Safety was...	1	2	3	4	5
<b>4 Supported employment services</b>	Access was...	1	2	3	4	5
	Timeliness was...	1	2	3	4	5
	Quality was...	1	2	3	4	5
	Safety was...	1	2	3	4	5

Circle the number next to each service and treatment received last year.	Please rate <b>each service and treatment received</b> on a scale of 1 to 5, with 1 being poor and 5 being excellent.	Poor	Fair	Good	Very Good	Excellent
<i>Circle one rating number per line</i>						
<b>5 Crisis intervention</b>	Access was...	1	2	3	4	5
	Timeliness was...	1	2	3	4	5
	Quality was...	1	2	3	4	5
	Safety was...	1	2	3	4	5
<b>6 Individual or group psycho-therapy</b>	Access was...	1	2	3	4	5
	Timeliness was...	1	2	3	4	5
	Quality was...	1	2	3	4	5
	Safety was...	1	2	3	4	5
<b>7 Treatment of substance abuse problem</b>	Access was...	1	2	3	4	5
	Timeliness was...	1	2	3	4	5
	Quality was...	1	2	3	4	5
	Safety was...	1	2	3	4	5
<b>8 Peer or other consumer-run programs/services/Support</b>	Access was...	1	2	3	4	5
	Timeliness was...	1	2	3	4	5
	Quality was...	1	2	3	4	5
	Safety was...	1	2	3	4	5

6. Do you or your loved one with a serious mental disorder also have a serious non-mental health condition (such as diabetes, asthma, heart disease, hypertension, HIV/AIDS)?

- 1 Yes
- 2 No (Go to Question 7)
- 3 Unsure (Go to Question 7)

6a **If yes**, is treatment being received for this medical condition?

- 1 Yes
- 2 No, need but cannot get treatment
- 3 No, treatment is not needed or wanted

7. What is your **current** living situation or the current living situation of your loved one with a serious mental disorder? (*Circle only one response.*)

In an apartment or single family home:

- 1 With spouse/domestic partner
- 2 With parents
- 3 With son/daughter under the age of 18
- 4 With other family member(s)
- 5 Alone
- 6 With friends/other adults
- 7 In a supervised community residence (such as a group home)

Other living situation:

- 8 In a nursing home
- 9 In a psychiatric inpatient hospital
- 10 In a correctional facility or jail
- 11 In a special school
- 12 Homeless or in a shelter for the homeless
- 13 Other
- 14 Unsure

8. Are you or your loved one with a serious mental disorder satisfied with the current residence or living situation?

- 1 Yes
- 2 Somewhat
- 3 No
- 4 Unsure

9. If you or your loved one with a serious mental disorder do not enjoy the most appropriate living arrangement, what barriers contribute to the problem? (*Circle **All** that apply.*)

- 1 Housing costs are too expensive
- 2 Appropriate housing is limited due to stigma against people with mental illness
- 3 Independent living is difficult because there are not good supports for consumers in the community to help them maintain an independent living arrangement
- 4 More structured residential care is not available
- 5 There is no financial assistance from the government to pay for housing and support
- 6 Family does not support living independently
- 7 Other (*Please specify*): \_\_\_\_\_
- 8 Unsure

10. Do you or your loved one with a serious mental disorder currently work at a job for pay?

- 1 Yes, full time (35 hours a week or more)
- 2 Yes, part time (less than 35 hours a week)
- 3 No (Go to Question 11)
- 4 Unsure (Go to Question 11)

10a. **If yes**, how long have you or your loved one held your (his or her) current job?

- 1 Less than 6 months
- 2 6 months to 1 year
- 3 More than 1 year
- 4 Unsure

10b. **If yes**, are you or is your loved one satisfied with your (his or her) current level of employment?

- 1 Yes
- 2 Somewhat
- 3 No
- 4 Unsure

11. What barriers (if any) to employment do you feel you or your loved one with a serious mental disorder has experienced? (*Circle ALL that apply.*)

- 1 None
- 2 Lack of jobs in the community
- 3 Stigma and discrimination against people with mental disorders
- 4 Lack of vocational services
- 5 Fear of losing health or disability income benefits
- 6 Inadequate treatment of mental health condition
- 7 Lack of transportation to job/employment services
- 8 Other (*Please specify*): \_\_\_\_\_
- 9 Unsure

12. Have you or your loved one with a serious mental disorder ever been arrested or detained by the police?

- 1 Yes
- 2 No (Go to Question 13)
- 3 Unsure (Go to Question 13)

12a. **If yes**, did the arrest or detention occur in the last year?

- 1 Yes
- 2 No (Go to Question 13)
- 3 Unsure (Go to Question 13)

12b. **If yes**, during this interaction with the correctional system or criminal justice system, did you or your loved one receive services or support in an effort to prevent unnecessary or inappropriate arrest or detention?

- 1 Yes
- 2 No
- 3 Unsure

12c. **If yes**, following this arrest or detention did you or your loved one receive needed mental health treatment?

- 1 Yes
- 2 No
- 3 Unsure

### **Services for Family Members of Individuals with Serious Mental Disorders**

13. Have you or your family members received family education services and support in the past year? (*Circle one.*)

- 1 Yes
- 2 No (Go to Question 14)
- 3 Unsure (Go to Question 14)

13a. **If yes**, what type of program did you or your loved one participate in? (*Circle ALL that apply.*)

- 1 NAMI Family-to-Family program
- 2 Journey of Hope
- 3 Other family led education/support program
- 4 Professionally led education/support program
- 5 NAMI support group participation
- 6 Other support group
- 7 Other (*Please describe*): \_\_\_\_\_
- 8 Unsure

13b. **If yes**, did you or your family members find the program helpful?

- 1 Very helpful
- 2 Somewhat helpful
- 3 Not that helpful
- 4 Not helpful at all
- 5 Unsure

### **Background Information**

Remember, if you are a consumer, please answer these questions as they pertain to **you**. If you are the family member or a friend of a person with a serious mental disorder, answer the questions as they pertain to him or her. If you are both a consumer and family member, please answer the questions as they pertain to you as a consumer.

14. What is your age or the age of your loved one with a serious mental disorder?

- 1 18-24 years of age
- 2 25-34 years of age
- 3 35-44 years of age
- 4 45-54 years of age
- 5 55-64 years of age
- 6 65-74 years of age
- 7 75 years of age or older

15. Are you or your loved one with a serious mental disorder ...

- 1 Male
- 2 Female

16. What is your current marital status or the marital status of your loved one with a serious mental disorder?

- 1 Married
- 2 Widowed
- 3 Divorced
- 4 Separated
- 5 Never married

17. Are you or your loved one with a serious mental disorder of Spanish, Hispanic, or Latino background or cultural heritage (i.e., Cuban, Mexican, Mexican American, Chicano, Puerto Rican, South/Central American, or other Spanish origin)?

- 1 Yes
- 2 No

18. How do you or your loved one with a serious mental disorder typically identify yourself? (*Circle ALL that apply.*)

- 1 White
- 2 Black or African American
- 3 American Indian or Alaska Native
- 4 Asian (i.e., Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or other Asian)
- 5 Native Hawaiian, Guamanian or Chamorro, Samoan, or other Pacific Islander
- 6 Other race (*Please specify*): \_\_\_\_\_

19. What is the highest level of education that you or your loved one with a serious mental disorder has completed?

- 1 Less than high school
- 2 Some high school
- 3 High school graduate/G.E.D. recipient
- 4 Some college
- 5 Undergraduate degree
- 6 Some graduate school
- 7 Graduate degree
- 8 Vocational or career development training
- 9 Vocational school certificate or diploma
- 10 Other (*Please specify*): \_\_\_\_\_

20. Do you or your loved one with a serious mental disorder currently receive income from any of the following sources? (*Circle ALL that apply.*)

- 1 Wages or salary from a job
- 2 Unemployment benefits
- 3 SSDI
- 4 SSI
- 5 State income supplements
- 6 VA benefits
- 7 Household income with spouse
- 8 Money on a regular basis from family
- 9 Retirement
- 10 Other source

21. What is the approximate total annual income of you or your loved one with a serious mental disorder?

- 1 Less than \$5,000 per year
- 2 At least \$5,000 but less than \$10,000 per year
- 3 At least \$10,000 but less than \$20,000 per year
- 4 At least \$20,000 but less than \$35,000 per year
- 5 At least \$35,000 but less than \$50,000 per year
- 6 At least \$50,000 per year
- 7 Not sure



22. Do you or your loved one with a serious mental disorder currently have any of the following types of health insurance plans? *(Circle ALL that apply.)*

- 1 Medicare
- 2 Medicaid
- 3 Veterans Administration health care coverage (VA, CHAMPUS/CHAMPVA)
- 4 Private health insurance (self-paid)
- 5 Private health insurance provided through an employer (fully-paid)
- 6 Private health insurance provided through an employer (employer contribution)
- 7 No insurance
- 8 Other
- 9 Not sure

23. How long have you or your loved one with a serious mental disorder been a member of NAMI? *(Please circle one response only.)*

- 1 Less than one year
- 2 One to five years
- 3 Six to ten years
- 4 More than ten years
- 5 I am not currently a NAMI member
- 6 Not sure

24. In the space provided below (and on additional pages if necessary), please share any positive or negative experiences you have gone through in the mental health care system, so that we can better understand the problems consumers and families face and how the services can be improved. *(Please print.)*

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*Thank you for completing this survey.*

Please return your completed survey in the enclosed postage-paid envelope  
by **March 21, 2003** to:

2003 Survey of Consumer/Family Views of Mental Health Services  
Colonial Place Three, 2107 Wilson Boulevard, Suite 300, Arlington, VA 22201



# TRIAD

Treatment/Recovery Information  
and Advocacy Database



**NAMI | TRIAD**

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2107 Wilson Blvd., Suite 300  
Arlington, VA 22201-3042

PH: 703-524-7600  
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[www.nami.org/triad](http://www.nami.org/triad)