

# Schizophrenia:

## Public Attitudes, Personal Needs

Views from People Living with Schizophrenia,  
Caregivers, and the General Public

Analysis and Recommendations



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June 2008



**National Alliance on Mental Illness**

*Schizophrenia: Public Attitudes, Personal Needs*

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The National Alliance on Mental Illness (NAMI), is the largest grassroots mental health organization dedicated to improving the lives of individuals and families affected by mental illness. NAMI has over 1,100 affiliates in communities across the country who engage in advocacy, research, support, and education. Members of NAMI are families, friends, and people living with mental illnesses such as major depression, schizophrenia, bipolar disorder, obsessive-compulsive disorder (OCD), panic disorder, post-traumatic stress disorder (PTSD), and borderline personality disorder.

NAMI is dedicated to the eradication of mental illnesses and to the improvement of the quality of life of all who are affected by these diseases.

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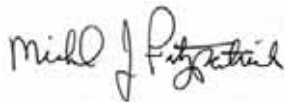
This report represents NAMI's analysis and recommendations of a survey conducted by Harris Interactive among the general adult public, people living with schizophrenia, and caregivers.

NAMI commissioned the survey in order to raise a national dialogue. Twice as many people today live with schizophrenia than with HIV/AIDS, yet many Americans know little about the disease.

Our specific goals were to measure public attitudes, identify gaps in knowledge and understanding, and provide an outline of the real experiences of those who live directly with the illness—which includes families and other caregivers. The survey also identifies where treatment and services are needed. They require public and private investment, which depends on public support—which ultimately depends on public attitudes. Lack of knowledge, misinformation, misperception, or misunderstanding, however, represent a public health crisis.

For the public attitudes section of the report, Harris Interactive polled approximately 1,000 members of the general public from February 13 –19, 2008, from a database of several million people who have agreed to participate in online research projects. Surveys of approximately 250 people living with schizophrenia and 250 caregivers were conducted online between February 11– 25, 2008, using NAMI e-mail lists.

Additional information, including methodology and detailed findings from the Harris Interactive survey can be viewed in the comprehensive electronic report available at [www.nami.org/survey](http://www.nami.org/survey). We hope you will join us in public discussions of the data as part of America's dialogue about the illness.



Michael J. Fitzpatrick, M.S.W.  
Executive Director  
National Alliance on Mental Illness

## Executive Summary

Imagine being homeless, or having a son or daughter who went missing and has not been heard from in years.

Imagine also fighting a health care system that is so fragmented that you can't get what you need to recover from a serious medical illness.

More than 2 million Americans and their families face these conditions every day because of an illness called schizophrenia.

It's an illness that is twice as common as HIV/AIDS.<sup>1</sup> It does not discriminate. It strikes people of all races and both genders, and cuts across all social and economic classes.

To better understand the impact of schizophrenia, NAMI, the National Alliance on Mental Illness, commissioned Harris Interactive to conduct a survey on attitudes and awareness among the general adult public, as well as among caregivers and individuals living with the illness.

*"I think the most important thing is to accept the disorder like any other medical disorder; that treatment works and that recovery is not only possible, but probable as well."*

*—individual with schizophrenia*

NAMI's introduction and analysis to the full Harris report highlights key findings from the survey, including important gaps in knowledge and understanding of schizophrenia, and makes recommendations to close these gaps.

Schizophrenia is a chronic, but manageable, disease. However, much more needs to be done to support treatment and recovery.

Two million Americans live with the illness. Only a third receive treatment. With medication, symptoms can often be controlled successfully: About 50% can improve significantly or recover completely over time.<sup>2</sup>

Treatment works—if a person can get it. As many of the findings of the report indicate, getting access to such treatment is a challenge. Individuals living with schizophrenia who participated in the survey in fact represent a special population because 95% are engaged in treatment. Most people living with illness are not.

The first section of NAMI's analysis, *Living with Schizophrenia*, discusses symptoms, diagnosis, and treatment.

The second section, *Public Attitudes*, discusses the social environment that affects treatment and recovery.

The third section, *Caregiver Experiences and Challenges*, discusses the relationship of caregivers and individuals with the illness and their respective needs.

<sup>1</sup> Drawing on the work Glynn et al., the Centers for Disease Control & Prevention (CDC) reports that an estimated 1,039,000 to 1,185,000 persons in the United States were living with HIV/AIDS in late 2003. See "HIV in the United States" at <http://www.cdc.gov/hiv/resources/factsheets/us.htm#1> (accessed May 22, 2008), and Glynn M, et al., *Estimated HIV Prevalence in the United States at the End of 2003*, National HIV Prevention Conference, June 12-15, 2005, Atlanta, Abstract T1-B1101.

<sup>2</sup> See Chapter 4, Adults and Mental Health, in U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General—Executive Summary*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999. Available online at <http://www.surgeongeneral.gov/library/mentalhealth/home.html> (accessed May 22, 2008).

All three help define living with schizophrenia in human, practical terms.

The survey results also reveal major gaps between what the public believes to be true about schizophrenia, what science tell us, and the real experiences and realities of individuals affected by the illness.

- Early intervention and treatment are critical to preventing long-term effects of the illness, but there is an enormous delay, averaging 8.5 years, between first experiencing symptoms to receiving treatment for schizophrenia.
- Many people with schizophrenia report that they have difficulty accessing other healthcare services and do not receive proper attention to other health concerns; this may be one reason why people with schizophrenia die on average 25 years sooner than the general population.<sup>3</sup>
- Public familiarity with schizophrenia is low, and public concern and fear is high. People recognize that it is a medical illness and that treatment works, presenting a paradox relative to attitudes.
- The public feels differently about people in treatment than it feels about people not in treatment; but still, to a large degree, people don't want to date, work for, or work with people with schizophrenia.
- Caregivers face many challenges in caring for their loved ones, both in terms of making sure the person they care for has access to treatment and services, as well as taking care of themselves. They report that they often feel isolated, lonely, worried, and burned out.
- Access to appropriate medications and services remains elusive for many, if not most, families and individuals.
- In spite of the tremendous hardship of the personal experience, the resilience of the human spirit emerges as one of hope, faith, and triumph for many.

Finally, NAMI's analysis offers recommendations that narrow the knowledge gap by dispelling myths and promoting understanding and the potential for recovery:

- Increase public education and awareness
- Close the gap between onset of symptoms and treatment
- Provide ready access to primary healthcare
- Increase access to treatment and services, including housing
- Ensure education and support for families and individuals living with schizophrenia

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<sup>3</sup> Parks J et al. (eds.) Morbidity and Mortality in People with Serious Mental Illness, National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council, Alexandria, VA, October 2006. Available online at [http://www.nasmhpd.org/general\\_files/publications/med\\_directors\\_pubs/Technical%20Report%20on%20Morbidity%20and%20Mortality%20-%20Final%2011-06.pdf](http://www.nasmhpd.org/general_files/publications/med_directors_pubs/Technical%20Report%20on%20Morbidity%20and%20Mortality%20-%20Final%2011-06.pdf) (accessed May 22, 2008).

- Invest in scientific and medical research advances

We must make a commitment to individual dignity and recognize that with proper treatment, services, and supports, horizons for people living with the illness can be restored. It is time to make recovery real.

## Introduction and Analysis

Schizophrenia affects more than 2 million Americans, or 1% of the nation's population age 18 or older. It is one of the most severe mental illnesses, one of the most feared, and yet also one of the most misunderstood.

People with mental illnesses die at least 25 years earlier than the rest of the population, compounding the cruelty of the disease, which can wear down a person's daily life and hopes for the future. People living with schizophrenia die from heart disease, diabetes, and other medical causes at a rate two or three times greater than the rest of the population.<sup>4</sup> Ten percent of people who struggle with schizophrenia die from suicide.

Yet schizophrenia is a manageable disease. Advances in medicine, including antipsychotic medications, psychosocial therapy, and rehabilitation, now enable many people who live with schizophrenia to recover and live productive, fulfilling lives.

Treatment works—if a person can get it.

### Living with Schizophrenia

*“My health insurance has a co-pay of 50% for mental health services but only \$10 for physical health services. I can't move out of my parent's house because it costs me \$350 a month just for therapy, the psychiatrist, and medication.”*

*—individual with schizophrenia*

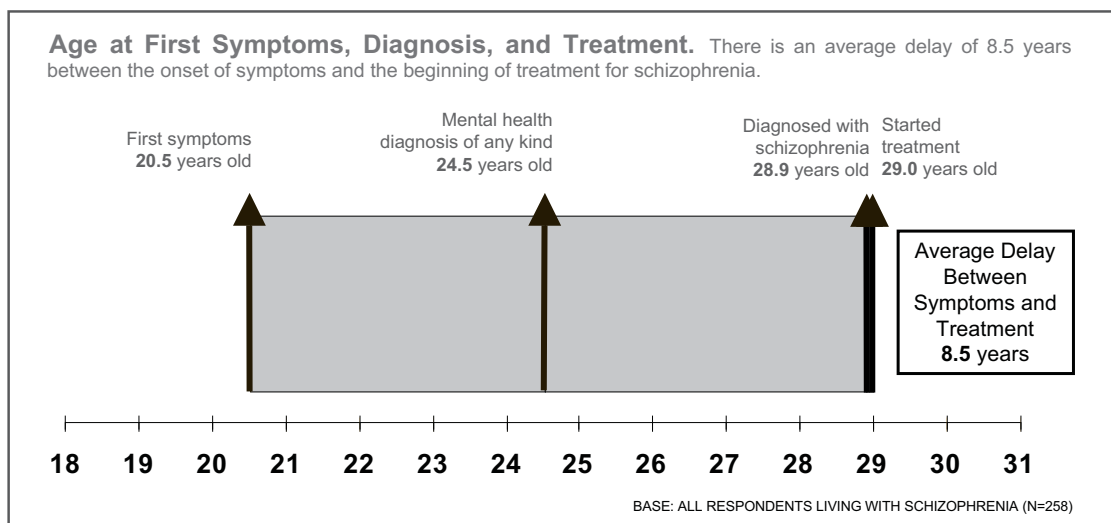
No single symptom signals schizophrenia. Any one of its symptoms also can be found in other mental illnesses, such as bipolar disorder or Alzheimer's disease. Observed over time, however, there are three types of symptoms that, in combination, may result in its diagnosis.

Positive, or “psychotic,” symptoms include delusions and hallucinations. These are symptoms that occur because a person “loses touch with reality” in certain situations. Negative symptoms include emotional flatness or lack of expression, an inability to start or finish activities, and lack of pleasure or interest in life. “Negative” does not refer to a person's attitude, but a lack of characteristics that should exist. The symptoms can resemble those of depression. Cognitive symptoms involve impairment of “thinking” processes, such as prioritizing tasks, organizing thoughts, and certain kinds of memory functions.

Diagnosis takes time. In clinical practice, symptoms generally need to be followed for at least six months. But neither time nor the illness wait for a diagnosis. The survey found the following:

- **People living with schizophrenia and in treatment, report an average delay of 8.5 years between the onset of symptoms and the beginning of treatment.**

<sup>4</sup> Ibid., at p. 15.



- Almost five years elapse between symptom onset and diagnosis of any kind of mental health condition. The average age of onset was 20.5 years old, with males generally experiencing symptoms two years earlier than females, and the average age of any mental health diagnosis is 24.5.

Schizophrenia is a disease that usually strikes at the threshold of adulthood—when young men and women in their teens and 20s are in school, entering the workforce, beginning families, or making other formative choices.

It has life-changing consequences, which can include lost or damaged relationships, disability, academic failure, unemployment, dependency, isolation, physical illnesses, jail or prison, and homelessness.

The survey offers evidence of diminished social and economic prospects even when a person receives treatment:

- Of the group, 56% receive Social Security Disability Income (SSDI); 51% Medicare; 45% Medicaid; 40% food stamps; and 34% Social Security Income (SSI).
- Not surprisingly, 63% of people living with schizophrenia have accepted money or financial support from family members or friends; 56% have depended on them for transportation; and 50% for housing.
- 59% of individuals living with schizophrenia under the age of 35 report decreased engagement in job searches.
- Only 29% receive vocational rehabilitation services, 20% job placement assistance, and 17% public housing—key supports that foster independence.
- Two areas of engagement increased for people diagnosed with schizophrenia: 38% report greater connection to religious or spiritual practices and 34% report an increase in volunteering—while 30% and 32%, respectively, report decreases.



The survey responses provide a sketch of what it is like to live with schizophrenia, but they reflect the experience of only a special population: 95% of individuals with schizophrenia who participated in the survey report that they are receiving treatment. In contrast, among the total population of people living with serious mental illnesses like schizophrenia, approximately two-thirds live without any treatment.<sup>5</sup> For them, life is even harder and grimmer.

Approximately 60% of people with schizophrenia die prematurely from heart disease, diabetes, or other conditions. This is a startling fact when considered alongside the following survey findings:<sup>6</sup>

- **People living with schizophrenia have difficulty getting healthcare for physical conditions. Nearly half (49%) say that doctors took their medical problems less seriously once they learned of their diagnosis; 39% say the diagnosis made it more difficult to get access to other physical healthcare.**<sup>7</sup>

Overall, people who live with the illness prioritize medical and social supports:

- **Nearly all say that access to a psychiatrist (95%), and medication and treatment (96%) are most helpful to improving their condition. A vast majority (93%) also believe that more effective medications and treatment, as well as better private health insurance (85%), would help improve their condition.**
- **Beyond these, access to crisis care (92%), hospital beds (83%), peer support groups (85%), assertive community treatment (77%), and care managers (76%) also are seen as helpful.**
- **A large majority believe that access to housing (88%), having a job (76%), and transportation (72%) would help improve their condition.**

These are supports and services that can help a person overcome the symptoms and consequences of schizophrenia. They also facilitate access to treatments for other health conditions. They reflect needs that support individual dignity.

How much is society willing to pay to improve the public health system to help 2 million Americans who become ill through no fault of their own? Inevitably, potential support is related to public attitudes.

## Public Attitudes

Americans are not sure what to think about schizophrenia. They are ambivalent; sometimes their views are contradictory. Knowledge can be accompanied by misunderstanding, goodwill by fear.

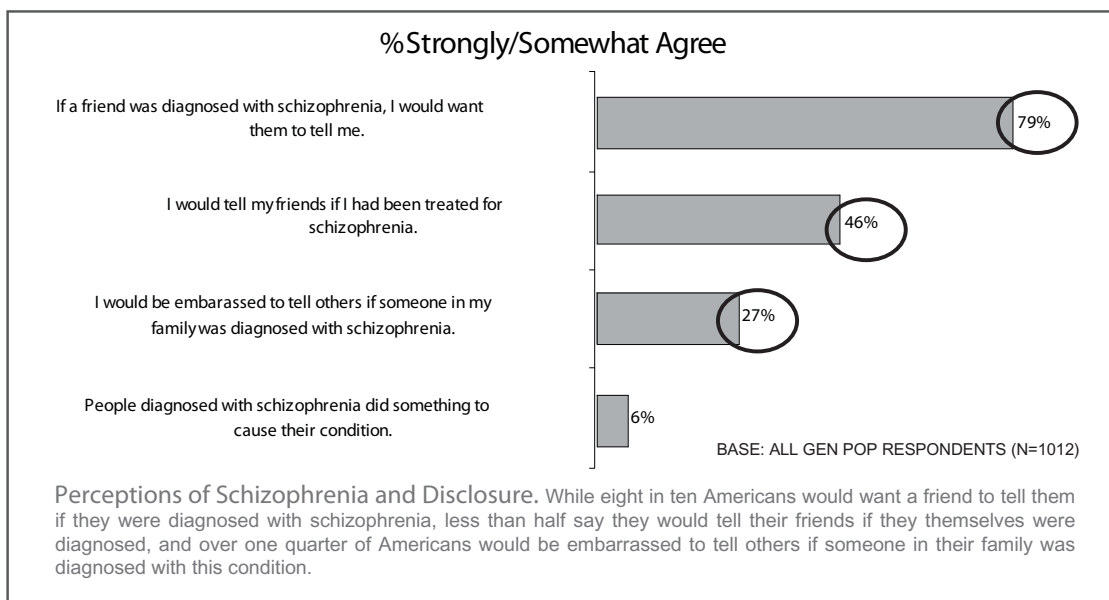
- **The good news is that the vast majority of Americans recognize that schizophrenia is an illness (85%) and that with ongoing care, people diagnosed with schizophrenia can lead independent lives (79%).**

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<sup>5</sup> Report of the Surgeon General, *op. cit.*, p. 411.

<sup>6</sup> Morbidity and Mortality, *op. cit.*

<sup>7</sup> At the same time, 82% of the survey's participants, who were living with schizophrenia, said that they knew they could rely on their mental health providers when they needed it.



- **But only one-fourth (24%) of the general public consider themselves to be familiar with the illness. In a list of 11 common medical conditions that included heart disease, cancer, diabetes, and depression, only Lou Gehrig's disease and multiple sclerosis ranked lower than schizophrenia in familiarity.**

While the public is more concerned about schizophrenia than some other illnesses, schizophrenia falls in the middle of a ranked list when comparing the proportion of people who say they are “very concerned” about a given illness.

- |                        |     |
|------------------------|-----|
| • Cancer               | 82% |
| • HIV/AIDS             | 81% |
| • Lou Gehrig's disease | 77% |
| • Multiple sclerosis   | 70% |
| • Heart disease        | 65% |
| • Schizophrenia        | 60% |
| • Diabetes             | 50% |
| • Bipolar Disorder     | 46% |
| • High blood pressure  | 37% |
| • Depression           | 33% |
| • Asthma               | 26% |

People mistake, overemphasize, or underestimate certain symptoms of schizophrenia. The greatest misconception (64%) is that “split or multiple personalities” are symptoms of schizophrenia.<sup>8</sup> Symptoms such as drug abuse (24%), alcohol abuse (23%), insomnia (41%), and disorganized speech (35%) are also not widely recognized.

Violent behavior as a symptom was selected by 60% of the public, which represents a fundamental fault line in how Americans view schizophrenia and other mental illnesses. Ironically, most

<sup>8</sup> Split or multiple personality is more precisely and respectfully known as *disassociative disorder*, resulting from psychological trauma. Its confusion with schizophrenia, a psychiatric brain disorder, lies in the latter's Greek word origins meaning “to split” and “mind.”

*“The public needs to fully understand schizophrenia first before people can begin to grasp the toll this illness takes on the individual affected by this disease and the physical and mental strain experienced by family members caring for the person afflicted by schizophrenia.”*

—caregiver

individuals with schizophrenia are not prone to violence; they typically withdraw from social interaction and simply prefer to be left alone.<sup>9</sup>

The U.S. Surgeon General reported ten years ago that although some research exists to support public concern, “the overall likelihood of violence is low” and the “overall contribution of mental disorders to the total level of violence in society is exceptionally small.” The “greatest risk” is from persons dually diagnosed with both a mental illness and a substance abuse disorder. There is also a “small elevation of risk” for persons with severe disorders such as psychosis, “especially if they are noncompliant with their medication.”<sup>10</sup>

Other studies support the U.S. Surgeon General’s basic assessment<sup>11</sup> and the National Institute of Mental Health (NIMH) has noted that substance abuse “always increases violent behavior, regardless of the presence of schizophrenia.”<sup>12</sup> Meanwhile, people with serious mental illnesses are as many as ten times more likely to be victims of violence than the general public.<sup>13</sup>

In any case, when it comes to perception, treatment is key.

Public attitudes toward people living with schizophrenia hinge on whether or not those people are receiving treatment. People are inclined to “distance themselves” dramatically from people not receiving treatment. Even though people understand that schizophrenia is a medical illness, the survey indicates that there are limits to openness.

- 79% of people would want a friend to tell them if they were diagnosed with schizophrenia, but only 46% say they would tell friends if they themselves were diagnosed.
- 27% would be embarrassed to tell others if one of their own family members was diagnosed.
- 80% expressed discomfort with the prospect of dating someone with schizophrenia who has not received treatment, compared to only 49% if the person has (received treatment).
- 77% would feel uncomfortable working with a person who has not received treatment, compared to only 24% if a person has.
- 80% would feel uncomfortable working for a person who has not received treatment, compared to only 34% if a person has.

<sup>9</sup> National Institute of Mental Health [www.nimh.nih.gov/health/publications/schizophrenia](http://www.nimh.nih.gov/health/publications/schizophrenia)

<sup>10</sup> Report of the Surgeon General, *op. cit.*, p. 7.

<sup>11</sup> See, for example, Steadman HJ et al. “Violence by People Discharged From Acute Psychiatric Inpatient Facilities and by Others in the Same Neighborhoods,” *Arch Gen Psychiatry*, May 1998; 55: 393-401, available online at <http://archpsyc.ama-assn.org/cgi/content/full/55/5/393> (accessed May 22, 2008); “New Factors Identified for Predicting Violence in Schizophrenia,” NIMH Science News (July 18, 2006), available online at <http://www.nimh.nih.gov/science-news/2006/new-factors-identified-for-predicting-violence-in-schizophrenia.shtml> (accessed May 22, 2008) and citing Swanson JW et al. “A National Study of Violent Behavior in Persons with Schizophrenia,” *Arch Gen Psychiatry*, 2006 May; 63(5): 490-9, available online at <http://archpsyc.ama-assn.org/cgi/content/full/63/5/490> (accessed May 22, 2008). The latter study reports on findings from the NIMH-funded Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE).

<sup>12</sup> Morbidity and Mortality, *op. cit.*

<sup>13</sup> Teplin LA et al. “Crime Victimization in Adults with Severe Mental Illness: Comparison with the National Crime Victimization Survey,” *Arch Gen Psychiatry*, Aug 2005; 62: 911-921. Available online at <http://archpsyc.ama-assn.org/cgi/content/full/62/8/911> (accessed May 22, 2008).

- 76% would simply be uncomfortable around a person who has not received treatment, compared to only 23% if a person has.
- 71% would be afraid for their safety around person who has not received treatment, compared to only 21% if a person has.

## Caregiver Experiences and Challenges

Mental illness affects the entire family. In the survey, more than two-thirds of caregivers (68%) are the parents or step-parents of the person living with schizophrenia to whom they provide care. Brothers and sisters comprised 12% of caregivers and 7% are spouses or significant others. Seven percent of caregivers are the children or grandchildren of the person under their care. The greatest challenge for all these family members is simply finding treatment providers and services for their loved ones.

- 82% say they have faced challenges in accessing services in the healthcare system.
- 79% say they are challenged by finding specialized services.

Caregivers' ranking of the factors that would be most helpful for improving the condition of the persons in their care closely mirrored that of the persons who live with schizophrenia.

- More effective medications and treatment (96%)
- Access to crisis care (95%)
- Access to medication and treatment (95%)
- Access to a psychiatrist (95%)
- Assertive community treatment (ACT) (94%)
- Access to peer support groups (93%)
- Integrated medical care with other conditions (92%)
- Access to a care manager (91%)
- Access to a hospital bed (90%)
- Access to housing (88%)
- Having a job (80%)
- Transportation (80%)

At the same time, the challenges caregivers face can be as significant as those affecting people living with schizophrenia.

- 41% of caregivers have provided care for more than ten years; 19% for more than 40 hours a week.
- 63% are challenged trying to find time for themselves; 57% in trying to manage time effectively.
- 55% face challenges in finding time to take care of their own health.
- The burden wears on family relationships: Approximately half of caregivers (51%) have felt taken advantage of by loved ones living with schizophrenia.

- **Caregiver concerns extend to other feelings.** Nearly all (90%) worry about what will happen to their loved ones when they die. More than 70% typically feel sad, protective, or frustrated when they hear others talking about the person they care for or others living with schizophrenia.

Less than half—but still a high proportion (43%)—indicate they are afraid of the person in their care. The U.S. Surgeon General’s Report on Mental Health has noted that risks of violence are higher for family members.<sup>14</sup> At the same time, the NIMH “Clinical Antipsychotic Trials of Intervention Effectiveness” (CATIE) study found that people diagnosed with schizophrenia who lived with their families and felt “listened to most of the time” had half the rate of violence of those who felt less supported.<sup>15</sup>

Worth noting is the fact that 71% of caregivers who took part in the NAMI survey believe that the condition of the person they care for would improve if caregivers received respite care.

## Recommendations: Improving Attitudes, Meeting Needs

### 1. Promote Public Awareness and Knowledge

Expanding access to treatment for people living with schizophrenia and helping them to achieve higher levels of recovery cannot happen without public support. That involves addressing public attitudes. Public education, heightening public awareness, and correcting public misperceptions will go a long way to eliminating the barriers that exist for so many.

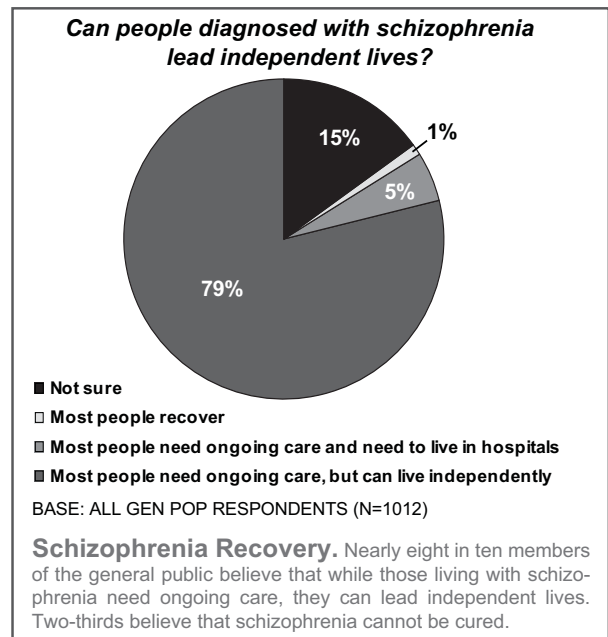
That’s easier said than done, but a framework for progress has slowly emerged over the past ten years to provide hope for the future. Strategies need to be expanded and intensified.

Showing the face of schizophrenia—through personal contact and stories of recovery—is one powerful agent for change. NAMI’s *In Our Own Voice* program<sup>16</sup>, in which individuals living with mental illness engage in public outreach and education, is one model that should be supported and expanded.

From a cultural perspective, partnerships, alliances, collaborations, and commitments that extend beyond the mental health community are essential. Accurate, balanced, compassionate reporting or portrayals in news and entertainment media are especially needed.

### 2. Close the Gap Between Onset of Symptoms and Treatment

Greater recognition of symptoms is needed—by individuals, families, primary physicians,



<sup>14</sup> *Ibid.*

<sup>15</sup> NIMH *Science News*, *op. cit.*

<sup>16</sup> See <http://www.nami.org/ioov> (accessed May 22, 2008) for more information.

teachers, and others, and particularly by professionals who interact with teenagers and young adults. Recognition can be promoted through greater education and training integrated into courses and programs.

It also can be supported through screening and evaluation programs such as the “Teen Screen”<sup>17</sup> program in high schools. Although Teen Screen focuses on depression, symptoms of stress and depression often precede or mingle with those of psychosis. Schizophrenia alertness needs to be included in individual evaluations that typically follow screenings.

Education and screening programs also need to be expanded in college and university settings, where the age of the population coincides with the average age of onset for schizophrenia. These programs need to be integrated with other healthcare services. Too often, alertness is lost in a fragmented system. The same holds true for teenagers and young adults who do not continue their studies after high school, but directly enter the work force or military service—and still require outreach.

No matter what the path, greater focus is needed on early intervention and prevention. Risk factors can be identified, managed, or treated before onset occurs. Early diagnosis and referral programs, such as those being promoted by the Robert Wood Johnson Foundation, should be supported and integrated into overall healthcare.<sup>18</sup>

### 3. Provide Welcoming Access to Primary Healthcare

Primary care physicians and other front-line health professionals need to understand the nature of mental illness and be trained to respond helpfully in addressing physical complaints and conditions. The need extends beyond the mental health community; it is an interdisciplinary, cultural challenge that must begin in medical and nursing schools—and must continue in practice settings, continuing education, and in-service trainings.<sup>19</sup> Meeting the challenge especially requires the commitment of professional and institutional leaders.

### 4. Increase Access to Treatment and Services

Full access to medications and other treatment must be preserved. In an effort to control costs, state Medicaid and privately-managed care regimes routinely restrict access to care through restrictive formularies and “fail first policies.”<sup>20</sup> Such restrictions ignore the fact that “one size does not fit all” and can lead to tragic consequences.<sup>21</sup>

Access to care must also include an end to unfair discrimination through mental health “parity” that extends to not just private, employer-paid health plans but also to Medicare.

An array of services is needed to ensure adequate treatment and promote recovery for people living with schizophrenia. In 2006, NAMI published *Grading the States: A Report on America’s Health Care System for*

<sup>17</sup> See <http://www.teencreen.org> (accessed May 22, 2008) for more information.

<sup>18</sup> For examples and resources, see <http://www.lifp.org/html/project/focus.html>, <http://www.schizophrenia.com/previ.htm>, and <http://www.schizophrenia.com/earlypsychosis.htm> (all accessed on May 22, 2008).

<sup>19</sup> One potential model is NAMI’s Provider Education Program. See [http://www.nami.org/template.cfm?section=Provider\\_Education](http://www.nami.org/template.cfm?section=Provider_Education) (accessed May 22, 2008) for more information.

<sup>20</sup> “Fail first” policies require that patients fail on one medication (or group of medications) before they can be reimbursed or prescribed another (usually more costly) medication. For a discussion of the types of policies states are using to contain psychiatric drug costs, see Koyanagi C et al., “Medicaid Policies To Contain Psychiatric Drug Costs,” *Health Affairs*, March/April 2005; 24(2): 536-544. Available online at <http://content.healthaffairs.org/cgi/content/full/24/2/536?ck=cnck> (accessed May 22, 2008).

<sup>21</sup> “Unnecessary Tragedy? Man Who Killed Mom Lost Access to Antipsychotics After Medicaid Cuts,” *Orlando Sentinel*, November 13, 2007.

*Serious Mental Illness*, which detailed “checklists for change.” The report noted that every state mental healthcare system requires carefully balanced levels of care. Cost-effective, proven treatment practices must be available.

Housing is an especially critical support for stability, recovery, and independence—and maintaining community connections. Along with employment, it needs to be seen as an integral part of the mental healthcare system.

## 5. Provide Education and Support for Caregivers and Individuals Living with Schizophrenia

Education and support are important to both individuals living with schizophrenia and their caregivers. Public-private partnerships at the national, state, and local levels are well suited to meeting this need, but they must be person-centered, community-based, and supported by providers. NAMI offers models through its own education programs<sup>22</sup>, including the following:

- **Peer-to-Peer:** a free course on relapse prevention and wellness for persons living with any mental illness diagnosis
- **NAMI Connection:** free recovery support groups that meet 90 minutes a week and are run by individuals living with mental illness for other persons who live with any diagnosis
- **Family-to-Family:** a free course for family caregivers of individuals with severe mental illnesses that discusses clinical treatments and teaches knowledge and skills that family members need to cope more effectively

## 6. Invest in Research

More effective medications and treatments are needed. In recent years, NIMH has funded CATIE, the largest comparative study of “old” and “new” generation antipsychotic medications. New generation medications have made dramatic differences in levels of recovery, but, overall, CATIE has found that the old generation remains generally as effective as the new. One size does not fit all; choices among medications are highly individualized and often involve managing side effects. The greatest implication of the study is the need for scientific and medical research that goes well beyond incremental improvements to the development of a more highly effective “third generation” class of medications.

As a society, we must make a commitment to individual dignity, support, and recovery. It will require changes in attitude and investment. Vision and will are needed from leaders in professions, business, industry, government, and media at all levels of society.

NAMI hopes this report will help inspire that commitment. Schizophrenia does not discriminate. It can strike any one of us or our loved ones. At any time, we or our loved ones may become one of the 2 million.

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<sup>22</sup> See <http://www.nami.org/programs> (accessed May 22, 2008) for more information.

# Acknowledgements

## Schizophrenia: Public Attitudes, Personal Needs

We would like to thank the many individuals living with schizophrenia and caregivers who participated in the schizophrenia survey. Their willingness to share their stories and experiences has been inspiring and insightful.

Our gratitude extends to the members of the Advisory Committee who contributed countless hours developing the scope of the survey and helping to integrate the findings to an insightful outcome. Their expertise was informative and their commitment to the report invaluable.

The survey was designed, administered, and results evaluated by the professional team at Harris Interactive. We thank them for contributing their expertise to the initiative.

Along with NAMI staff who served on the Advisory Committee, additional NAMI staff who contributed to the initiative include Charles Harmon, Director of External Relations; Ronald Honberg, J.D., Director of Policy and Legal Affairs; Angela Kimball, Director of State Policy; Don Lamm, Director of Web Services; Dan Waggoner, NAMI Intern.

### NAMI Advisory Committee members:

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