

First Episode: Psychosis

Results from a 2011 NAMI Survey





National Alliance on Mental Illness

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NAMI, the National Alliance on Mental Illness, is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI advocates for access to services, treatment, supports and research and is steadfast in its commitment to raising awareness and building a community of hope for all of those in need.

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Introduction

In July 2011, NAMI (National Alliance on Mental Illness) conducted an online survey of individuals who have experienced psychosis firsthand or directly witnessed the experience of a family member or friend.

Psychosis is not a diagnosis but a symptom or set of symptoms that can have many different causes. Psychosis may be transient, intermittent, short term or part of a longer term psychiatric condition. Early identification and evaluation of the onset of psychosis is an important health concern as outcomes are improved with earlier detection and intervention.

Psychosis is defined as a loss of contact with reality. It typically involves at least one of two experiences:

- Hallucinations which can be auditory in nature (*e.g.*, hearing voices), less commonly visual experiences and more rarely, smelling things that no one else perceives. For the person who experiences hallucinations, they are very real.
- Delusions which are false fixed beliefs, which may involve paranoia (*e.g.*, a man who believes the FBI is chasing him) or mistaken identity (*e.g.*, a woman who believes her mother is an imposter). What makes beliefs delusional is that they do not change when a person is presented with new ideas or facts that demonstrate they are false.

Psychosis is a condition that has historically been associated with shame, humiliation and prejudice, which makes the need for better information more important. NAMI believes that information helps individuals and families make better choices and helps reduce the isolation so common to these experiences.

In response to strong demand from NAMI's community of individuals and families affected by mental illness, NAMI initiated this survey and as part of a project that includes new resource materials on its website: www.nami.org/psychosis. The survey follows another NAMI survey, *Schizophrenia: Public Attitudes, Personal Needs* (2008) which found that an average nine year gap occurs between symptoms and the beginning of treatment.

Unnecessary delay in evaluation, diagnosis and treatment represents a public health crisis. Meeting that crisis requires changes in education and culture, as well as the health care system. It requires state-of-the-art resources.

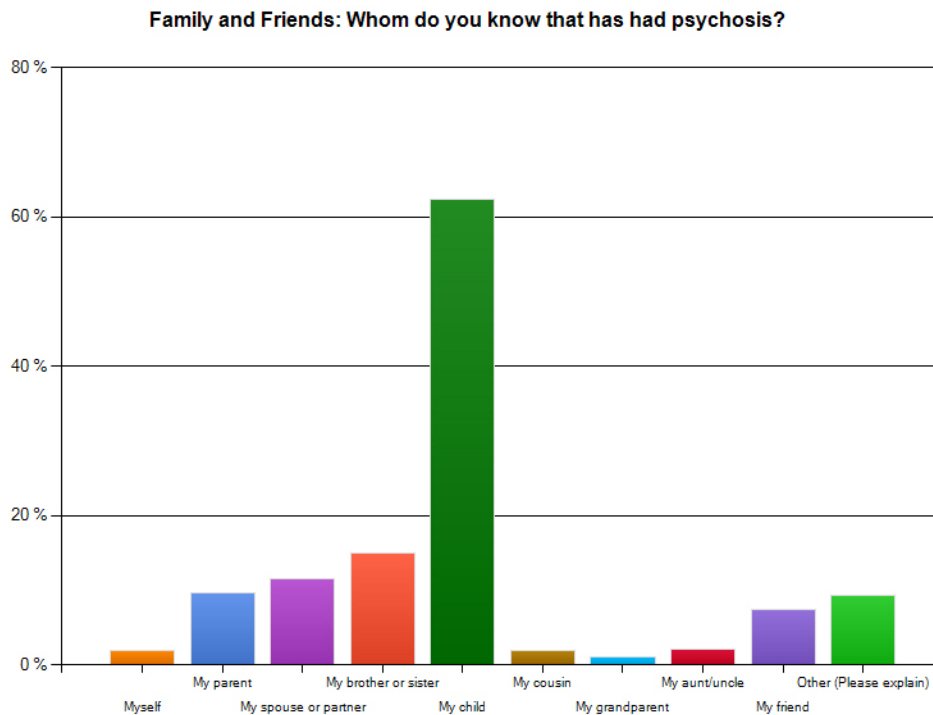
With this survey, NAMI has sought to identify needs expressed directly by the people who have the most at stake (*i.e.*, individuals who are at risk of experiencing a first episode of psychosis, those who are recovering from one and their family and friends).

Survey Scope

NAMI conducted the survey online from July 15 to July 26, 2011. There were 1,215 responses by persons who identified themselves as having personally experienced psychosis. There were 2,882 by persons who had witnessed someone in early stages of psychosis. In both instances, the respondents were overwhelmingly white, female and with at least a college education¹

The average age of those persons who had experienced psychosis was 24 at the time symptoms first began. The oldest age at time of onset was 63 and the youngest age three.²

Among family members and friends, parents provided the greatest number of respondents who had witnessed early stages of psychosis in a person: 62.4 percent. The four largest other subgroups were siblings (15.1 percent), spouses or partners (11.5 percent), the person's own children (9.6 percent) and friends (7.5 percent).



Insight into Symptoms

A dramatic difference exists in responses between individual who experienced psychosis and other persons as to who first knew something was wrong and whether intervention occurred. This disparity may illustrate the complexity of recognizing symptoms and the challenge of discussing them openly—even between people who love each other.

Approximately 40 percent of individuals who experienced psychosis said initial insight came from recognizing symptoms themselves, while only 18.2 percent said their parents saw the symptoms first and intervened. Among family and friends, only 13.1 percent said the person recognized symptoms and knew something

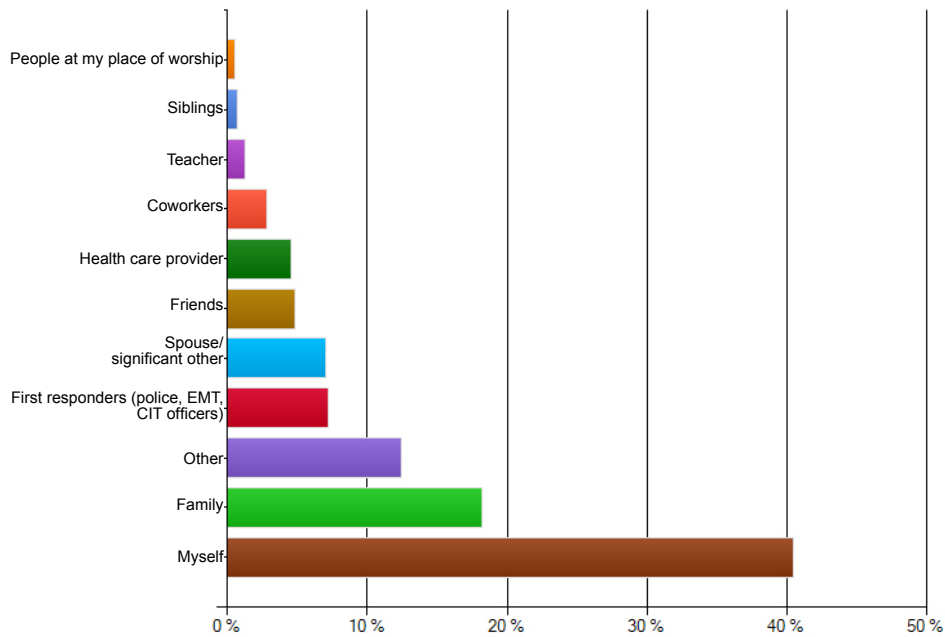
1 Among those who had experienced psychosis, 82.8 percent were white, 73.7 percent female and 45.7 percent had completed college and 23.6 percent had a graduate degree. Three percent were African American, 2.8 percent were Asian American, 2.7 percent Hispanic, 0.9 percent American Indian or American Native and 4.1 percent multiracial. Among family and friends, 85.3 percent were white. 85.5 percent were female, 45 percent had completed college and 35.6 had graduate degrees. In this group, the number of Hispanic respondents was higher, 4.2 percent, followed by 3 percent African American, 1.1 percent Asian American and Pacific Islander, 0.5 percent American Indian or American Native and 2.5 percent multiracial. In both groups, approximately 4 percent declined to identify racial background.

2 The survey allowed for responses based on best estimates and being told by others about their experience.

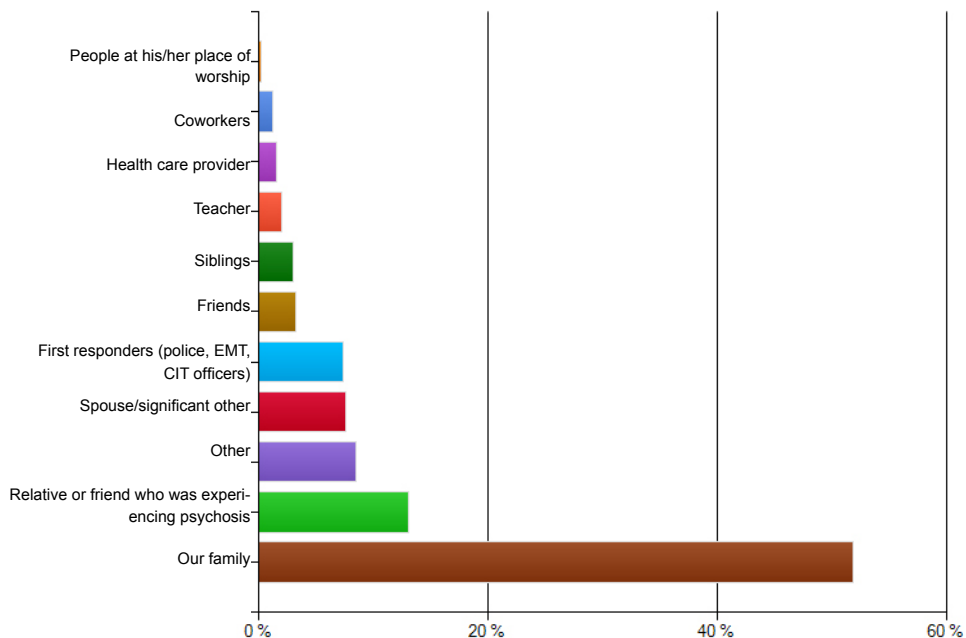
was wrong. Approximately 50 percent said it was the family who recognized symptoms and intervened. Only 4.5 percent of individuals who experienced psychosis credited health care providers for recognizing symptoms and intervening: Only 1.6 percent of family and friends did so. This suggests that, based on these results, health care providers appear to be downstream in the process for most people.

Higher proportions (7.2 percent and 7.4 percent respectively) credited “first responders” such as police and emergency medical technicians for recognizing symptoms and intervening. Proportionately, the gap between providers (1.6 percent to 4.5 percent) and first responders (7.2 percent) is small, but it may still reflect that recognition and intervention in the onset of mental illness comes more often at a crisis point than in a doctor’s office.

Individual who experienced psychosis: Who first recognized the symptoms of your early onset psychosis?



Family and Friends: Who first recognized the symptoms of your relative or friend’s early onset psychosis?

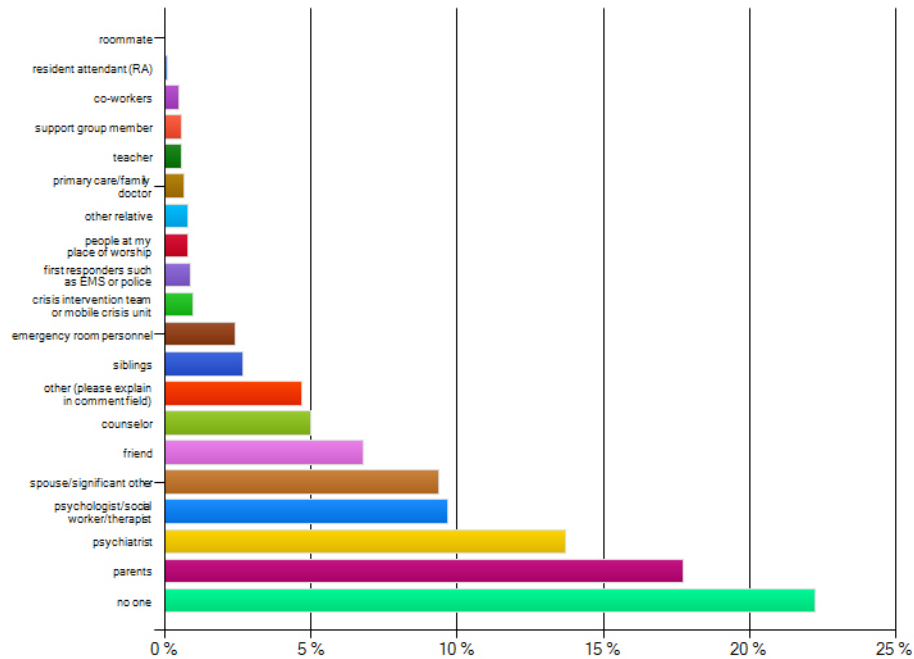


Most Helpful Persons

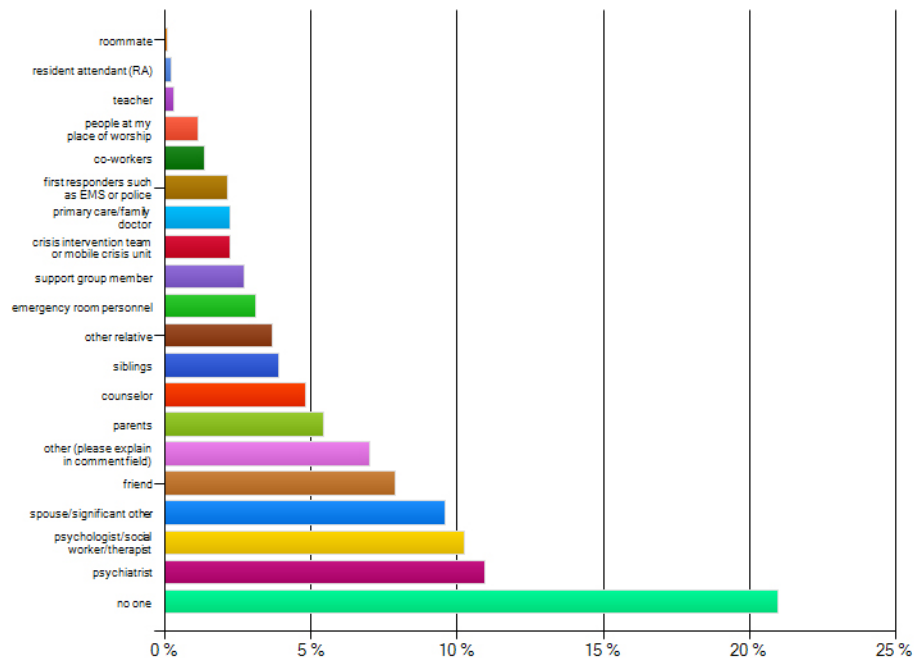
When asked who was most helpful to a person during early stages of psychosis, it is striking that many individuals who experienced psychosis and family and friends answered “no one,” *i.e.*, 22.2 percent and 21 percent respectively. For both groups, this was the greatest proportion among responses—suggesting a high level of isolation and desperation.

People don’t know where to turn. They may go looking in wrong places. People who want to help may not know what to do.

Individual who experienced psychosis: Who was most helpful to you?



Friends and Family: Who was most helpful to you?



I knew something wasn't right but I was afraid to tell anyone about my thoughts... Then I got to a point that I was so wrapped up in those delusions and hallucinations I was helpless."

-Person who experienced psychosis

For those who experienced psychosis, 17.7 percent said their parents were most helpful; 13.7 percent their psychiatrist, 9.7 percent a psychologist, therapist or social worker and 9.4 percent their spouse or significant other. Among family and friends, 10.9 percent said it was a psychiatrist, 10.2 percent a psychologist, therapist or social worker, 9.6 percent a spouse or significant other and 7.9 percent a friend.

In survey comments, individuals who had experienced psychosis indicated many ways in which a person or persons had helped them:

- Identifying problems early
- Listening patiently and compassionately, without making judgments
- Making suggestions without being confrontational; remaining gentle and calm
- Keeping them from harming themselves
- Taking them to an emergency room or making appointment and taking them to a doctor
- Providing a safe place to rest or recover
- Flying or driving long distances to be with them
- Explaining the nature of the illness and what was happening
- Building trust by making decisions together;
- Prescribing the right medication
- Prescribing cognitive behavioral therapy
- Providing child care, cooking or taking on other daily chores
- Providing financial support
- Encouragement that "normalized the experience," such as to finish school or return to work

Family and friends who responded indicated ways in which a person or persons had helped:

- Alerting them to symptoms; help in monitoring
- Referring them to psychiatrists or counselors
- Recommending NAMI's education and support programs
- Providing information and explanations
- Providing moral support; listening
- Sharing stories
- Providing spiritual guidance and support
- Helping with other responsibilities; cooking; child care
- Financial assistance

Information, Support and Assistance

Individuals who experienced psychosis sought help—information, support or other kinds of assistance—from a variety of sources. Survey responses primarily indicated psychotherapy or counseling (83.1 percent), mental health providers (81.3 percent), family members (70.1 percent) and friends (62.4 percent). For many (53.8 percent), the Internet was a source of information.

Family and friends indicated that they sought information, support or other assistance from friends (65.9 percent), family (62 percent), NAMI resources (59.5 percent), the Internet (54.0 percent), support groups (45.3 percent) or psychotherapy or counseling for themselves (40.2 percent).³

In all cases, family, friends and the Internet stand out as major sources of information, support and assistance that complement or supplement treatment and support from mental health providers.

For individuals who experienced psychosis, the most helpful information or resources included:

- Websites
- Books and pamphlets
- Group therapy and peer support
- Outpatient programs
- High school or college counseling centers
- Hearing positive stories about people who experienced psychosis and the impact on their lives
- Spiritual practices,, including reading the Bible or listening to soft, reassuring music

The responses often expressed awareness that many sources of information and support did not exist until the 1990s. They also cautioned about which books or websites on which to rely (*i.e.* “Don’t believe everything you read.”) Websites mentioned positively tended to be the Depression and Bipolar Support Alliance (dbsa.org), the Mayo Clinic (mayoclinic.com), NAMI (nami.org), the National Institute of Mental Health (nimh.gov), PsychCentral.com and Web M.D. (webmd.com) “Self help” books and workbooks were recommended in general, while *An Unquiet Mind* by Kay Redfield Jamison was specifically and frequently mentioned.

Family and friends provided similar or overlapping responses:

- Websites
- Books and pamphlets
- Health care providers
- Family and friends
- NAMI education and support programs

Books specifically and frequently mentioned were *I’m Not Sick, I Don’t Need Help: How to Help Someone with Mental Illness Accept Treatment* by Xavier Amador, Ph.D. and *Surviving Schizophrenia: A Manual for Families, Consumers and Providers* by E. Fuller Torrey, M.D.

³ In this survey area, respondents could check all answers that applied to them. “NAMI resources” potentially includes print literature, website information, electronic newsletters, and education and support groups. At the same time, “support groups” may include ones run by other organizations.

Immediate Needs

Survey comments by respondents who had experienced psychosis indicated a range of immediate needs during the period of crisis. They included:

- Getting rid of voices and paranoia
- Knowing the difference between what was real and unreal
- Hospitalization, medication and stabilization
- A safe place and protection
- Access to a good psychiatrist or counselor
- Sleep
- Validation of their experience; someone to listen who could be trusted
- Information and explanation
- Financial assistance

In some cases, the comments reflected conflicting or competing needs. What works best for one person is not necessarily the same for other people.

Many respondents considered a hospital to be “a safe place,” while others found the prospect of hospitalization terrifying. Living at home with parents or other family members was a common preference (especially if their illness forced them to give up apartments or other living arrangements), but in some cases “home” was not an option because of domestic or sexual abuse. In other cases, an alternative to homelessness—living on the street—was the immediate need.

Many people who indicated that medication as an immediate need during the onset of psychosis also indicated that they would not have said so at the time of their psychosis, in part because they did not see themselves as sick at the time.

Family and friends offered some similar, but also somewhat different needs:

- Keeping the person safe
- Finding the right help
- Knowing what to do if the person refuses help
- Finding support and answers; understanding what is happening
- Dealing with privacy laws in order to get information from health care providers
- Navigating the health insurance system; finding money to pay for care
- Time—for work, caring for the rest of the family and for themselves

“It’s the most soul-wrenching experience anyone can go through. Use every resource to get through it and then turn around to help those coming up the mountain after you. They need your help.”

-Person who experienced psychosis

Challenges

In survey comments, individuals who had experienced psychosis indicated a range of issues they found most challenging.

- Telling other people; confronting stigma
- Knowing what to believe; separating reality from delusion
- No longer being taken seriously by others
- Not being able to function well
- Starting over; not knowing where to start or “what’s next” or being able to “picture a future”
- Continuing school or returning to work
- Taking medication; side-effects
- Financial survival; meeting family responsibilities
- Finding the right doctor or therapist and medication
- Suicidal thoughts
- Not being able to stand up for themselves

Family and friends indicated a range of issues that they had found most challenging.

- Getting health care providers to talk frankly about the best way to handle things
- Balancing work and other needs
- Taking care of themselves
- Maintaining a social life
- Dealing with stigma—being blamed for being a bad parent
- Sadness and grief over the illness and trauma
- Constantly picking up the pieces
- Relationships with parents, siblings and friends
- Finances

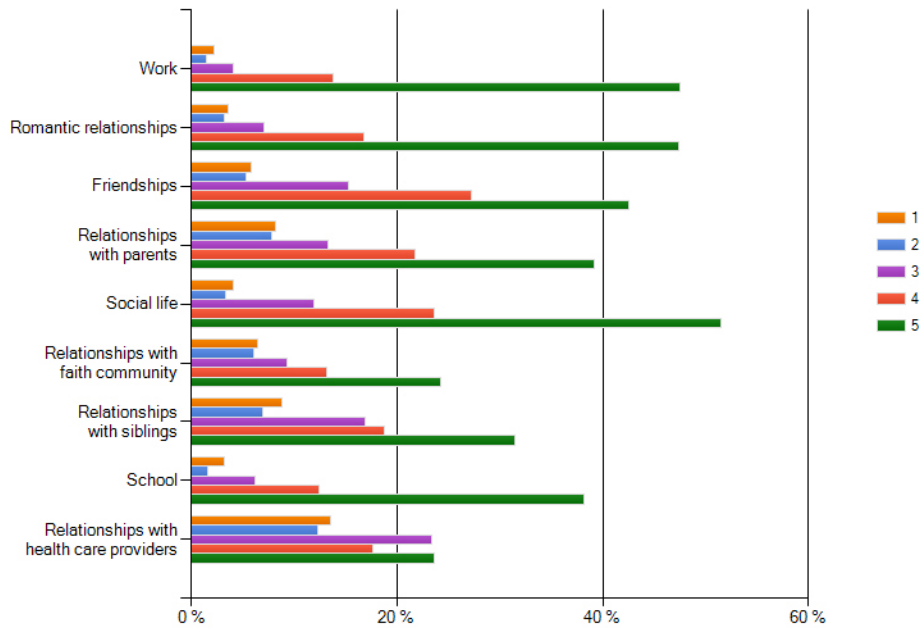
“The illness affects the entire family, including how family members interact with each other... Be loving and patient with each other. Go to a family counselor if you feel that your family may be falling apart.”

-Family member

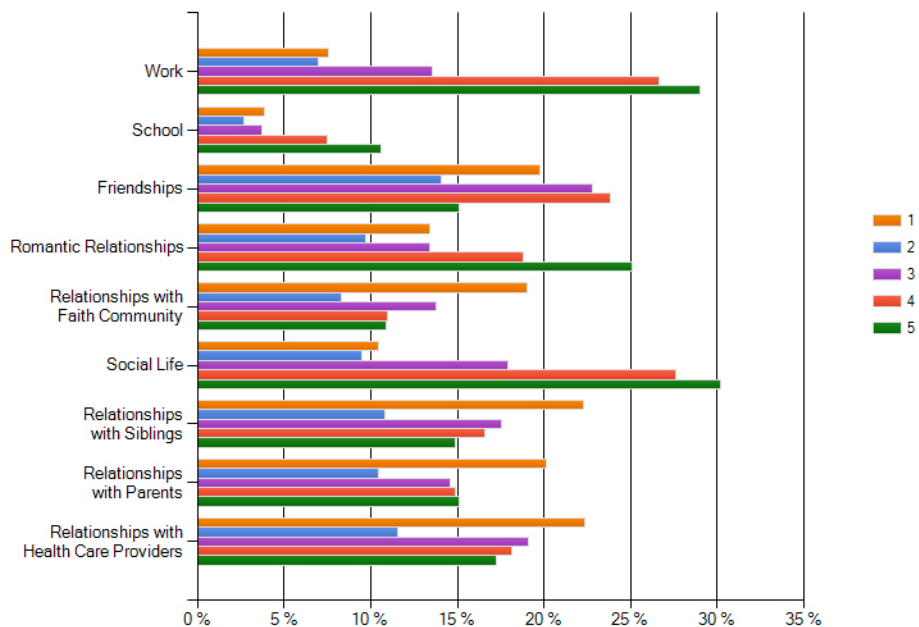
Most Difficult Challenges

NAMI asked each group to indicate on a scale of 1 through 5 the level of difficulty in managing aspects of daily life. On the scale, 4 was “somewhat difficult” and 5 was “very difficult.” Individuals who experienced psychosis rated social life as very difficult (51.1 percent) followed by work (47.5 percent) romantic relationships (47.4 percent), friendships (42.6 percent) and relationships with parents (39.2 percent). For family and friends themselves, social life (30.2 percent), work (28.9 percent) and romantic relationships (25.1 percent) became very difficult. Almost 50 percent also said that friendships became either “somewhat difficult” (23.8 percent) or “very difficult (15.1 percent).

Individuals who experience psychosis: Rate aspects of managing daily life during your first episode. 1= Not very difficult 2= Somewhat not difficult 3= Neither difficult nor easy 4= Somewhat difficult 5= Very difficult



Family and friends: Rate the level of difficulty you experienced managing your daily life during your family member's or friend's first episode of psychosis. 1= Not very difficult 2= Somewhat not difficult 3= Neither difficult nor easy 4= Somewhat difficult 5= Very difficult



Substance Use

Most individuals who experienced psychosis and their family and friends believed that substance use had no impact at the time of the person's first psychotic experience.

Two-thirds (66.6 percent) of respondents who had experienced psychosis said no, along with 46.4 percent of family and friends. Those who believed substance abuse played a role were 30.5 percent of the individuals who had experienced psychosis and 38.9 percent of family and friends. Almost 15 percent of family and friends were unsure.

Information That Would Have Been Helpful

The survey asked both groups what kind of information would have been helpful to them at the time of first experiencing or witnessing psychosis. The results were very similar, with a few minor differences. For the person who experienced psychosis, information about treatment and services (89 percent), the illnesses associated with psychosis (87 percent) and how to get the most from a doctor and the health care system (85 percent) ranked at the top of the list. Family and friends gave these areas the same order of priority, but with slightly higher proportions: 95.3 percent, 94 percent and 93.3 percent respectively.

Both groups would have liked information about how to share the experience with others: 79.7 percent and 79.4 percent respectively. Eighty-one percent of family and friends would have found information about navigating health insurance system to be helpful, while only 68.6 percent of individuals who had experienced psychosis indicated a desire for such information. Among family and friends, 62.6 percent would have found information about the possible role of substance abuse in psychosis to be helpful, while only 42.7 percent of those had experienced psychosis would.

Suggestions for People in Psychosis

Individuals who had experienced psychosis offered many helpful suggestions to people who might experience it for the first time—including suggestions of resources they had not had themselves, but wish they had.

- Find the right doctor, keep appointments and take your medication
- Find your spiritual strength
- Know what “triggers” your psychosis; avoid them
- Learn stress reduction and management
- Keep a sense of humor
- See a doctor right away when it starts
- Get cognitive behavioral therapy
- Be selective about whom and what you tell, but stay connected to others
- Do what you can incrementally
- Do puzzles and read books
- Yoga
- Don't look back; move forward
- Take care of all the areas of your life: sleep, proper diet, spiritual and social needs, relaxation
- Listen to or read stories of positive role models; people who have had similar experiences
- Learn to trust and cooperate; don't fight

Family and friends offered their own suggestions:

- Get counseling and mental health support for you
- Connect with NAMI
- Educate yourself and join a support group
- Hang in there; remember that you are not alone
- Even if no one agrees with you, seek help as soon as possible
- Find a good doctor and mental health care providers
- Don't argue when a person is experiencing psychosis
- Reach out to family, friends and your faith community
- Remember to take it one day at a time
- Don't be afraid to ask questions or advocate
- Be patient
- Understand that medication takes time

Summary and Conclusion

The survey produced several major findings, as well as practical advice that should be considered carefully.

- Differences in perceptions exist—almost in converse proportions— between individuals who experienced psychosis and their families and friends as to who knew something was wrong and help was needed. To some degree, the disparity may illustrate the complexity of recognizing symptoms and the challenge of discussing them openly between people who care about each other.
- Only a small percentage of both groups credited health care providers as having recognized symptoms—which suggests that providers become involved only “downstream” in the process. A somewhat larger, but still small percentage from each group credited “first responders” such as police or emergency medical technicians. To some degree, the results suggest that recognition and intervention in the onset of mental illness comes more often at a crisis point, rather than in a doctor’s office.
- Approximately 20 percent of both individuals who experienced psychosis and their families and friends felt that “no one” helped when the onset of symptoms occurred. This was the single greatest proportion of responses to a question about who had been “most helpful,” suggesting a high level of isolation and desperation. When help was found, it was most often through family members and friends, followed by a psychiatrist or psychologist, therapist or social worker.
- Responses reflect different phases and priorities in needs as a person moves from the first episode of psychosis to a longer period of crisis and then the challenge of recovery. “Recovery” may itself involve different levels and a “changed world” overall for both the individual and family and friends. “Help” encompasses a broad spectrum of continually evolving needs.
- A range of sources for information, support and assistance exist, but they are often fragmented, uncoordinated or difficult to find. Providers do not necessarily refer individuals or families to complementary or supplementary programs in the community, such as support groups. Families and individuals report that their needs for information regarding their experience with early episode psychosis are met through their own resourcefulness, usually through the Internet or informal networking.

Each of these findings and the summarized, bulleted lists in the report offer guidance for strengthening mental health care reform—as well as problem-solving in particular cases. NAMI hopes that it will be used for those purposes, along with resources at www.nami.org/psychosis.

Psychosis is terrifying. One person called it a “soul-wrenching experience.” Another feared relapse “more than anything else, including death.” Family members and friends expressed “grief” over changes that it may inaugurate in a loved one’s life. At the same time, a constant, common theme in personal comments was the encouragement not to give up. Hold on to hope, love and patience. Recovery is possible. We are all still whole.

It is that with the spirit of hope and commitment that NAMI offers these findings and the vision of helping others. The best hope, of course, will come from preventing first episodes of psychosis or minimizing the impact of those episodes that do occur.

Acknowledgements

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Download this report at www.nami.org/psychosis/report.

**“It’s scary and devastating,
but eventually you adjust to a ‘new normal.’
The world hasn’t ended—a different world has begun.”**
-Family member



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