CLASS 2

CLASS HANDOUTS

Class 2: Handout # 1
Vocabulary/Pronunciation

adrenal:	ah – dreen – al
alogia:	a – loge – ya
anhedonia:	an – he – doanya
autism:	awe – tism
avolition:	ah – vo – lish – un
bizarre:	biz – zar
catatonic:	catta – tonic
circuitry:	sir – cut –tree
deficits:	deffa – sits
dysphoric:	dis – for – ic
dystrophy:	dis – tro – fee
euphoric:	you – for – ic
hallucinations:	ha – loo – si – nay – shuns
metabolism:	me – tab – bolism
prodromal:	pro – drome – al
psychopathic:	sy – co – path – ic
psychosis:	sy – co – sis residual: ree – zidyu – all
schizoaffective:	skiz – o – ah - fec – tive
tangential:	tan – gen - shul

Class 2: Handout # 2
What are the Basics We Need to Know about Psychotic Illness, Starting with Schizophrenia?

Schizophrenia is a devastating brain disease whose acute stage always involves a psychotic episode. The name "schizophrenia" means "to split the mind"—a term which vividly captures the idea of a complete break between reality and psychotic thinking.

It is now evident that schizophrenia involves some fundamental alteration of the brain. A recent article concludes, (quote) "Schizophrenia is a disorder of brain circuitry, not some mysterious demon. Increasing evidence points to abnormalities that arise very early in life, probably before birth, which disrupt the normal development of the brain."

This modern biological explanation has not always held sway. Along with infantile autism and other developmental disorders (which are now known to involve specific brain dysfunctions), schizophrenia was attributed to maternal mistreatment; primarily neglect, disinterest, callousness, etc. Unfortunately, 50 years of clinical literature has blamed mothers, or families, for "causing" this severe brain disorder in their offspring.

The fact is, the characteristic "signs and symptoms" of schizophrenia have been observed for centuries. Moreover, they are universal as they are experienced by individuals living with schizophrenic illness. The World Health Organization sponsored an international study to determine if persons with schizophrenia from different countries were alike when diagnosed by a group of clinicians using the same interviewing techniques and trained to use the same decision rules. The findings: a person with schizophrenia, whether living in China, Colombia, the Czech Republic, Denmark, India, Nigeria, the United Kingdom, the USA or Russia exhibited lack of insight, suspiciousness, unwillingness to cooperate, false ideas, emotional dullness, poor rapport, and auditory hallucinations.

Although schizophrenia has been shown to affect all racial and ethnic groups at the same rate, people from diverse communities are often over diagnosed with this illness. For example, one large study conducted by the Veteran's Administration found that African Americans were more than 4 times as likely to be diagnosed with schizophrenia as Caucasians. The same study found that Latinos were 3 times more likely be diagnosed with this illness than Caucasians. It is extremely important for family members from all ethnic communities to understand the diagnostic criteria for these illnesses.

The general public tends to confuse schizophrenia with "split personality" (which it is not), or with rational thinking that goes in opposite directions (which it is not), or demonizes schizophrenia as psychopathic behavior (which it is not). Schizophrenia is a common brain disorder which affects 1 out of 100 people, typically striking them down in the prime of their early adult years. It is far more common than many other disorders which we hear much more about, like multiple sclerosis or muscular dystrophy ("Jerry's Kids").

Class 2: Handout # 3
Diagnostic Criteria for Schizophrenia

CRITERION A: 2 (or more) of the following for at least 1 month:

- Delusions
- Hallucinations
- Disorganized speech
- Grossly disorganized or catatonic behavior
- Negative symptoms such as: Alogia (decreased speech), avolition (lack of motivation), flat or blunted affect (emotional responses), inappropriate affect (such as crying, laughing or yelling inappropriately), inability to relate to others

Note: Criterion A does not require a second set of symptoms if there are bizarre delusions, auditory hallucinations of a voice providing running commentary or two or more voices talking to each other.

Criterion B: Social and occupational dysfunction

Criterion C: Some symptoms must persist for 6 months or more

Criterion D: Schizoaffective disorder, depressive disorders and bipolar disorders with psychotic features have been ruled out

Criterion E: Disturbance is not attributable to physiological effects of substances or another medical condition

Criterion F: Symptoms are independent and additional to any existing Autism Spectrum Disorder

Phases of Schizophrenia:

Prodromal Phase	Acute Phase	Residual Phase
May build slowly and subtly over years	*Must be at least one month long*	*Can last years*
Negative symptoms often start in this phase **Behaviors:** Social withdrawal Decline in function Less attention to hygiene Odd, peculiar behaviors Developing unusual rituals **Thinking:** Suspicious, superstitious Illogical or odd beliefs **Senses:** Odd sensory experiences such as illusions (misinterpretation of a sensation such as seeing a shadow and thinking it is a monster or believing that you are hearing words in the midst of radio station)	May continue negative symptoms from prodrome but may become more anxious, irritable and angry (showing more intense affect than in the other phases) **Behaviors:** Grossly Disorganized Behavior In rare cases, catatonic rigidity (bizarre body postures, mutism) or catatonic excitement (intense agitation) **Thinking:** Grossly Disorganized Speech Delusions **Senses:** Hallucinations	Negative symptoms are often the most disabling symptoms during this phase May develop depression **Behaviors:** Similar to prodrome but may have a lower level of functioning Some disorganized behavior may persist **Thinking:** Cognitive deficits often persist Delusions may persist but are less intense than the acute phase **Senses:** Hallucinations may persist but are less intense than in the acute phase

Sources: Diagnostic and Statistical Manual (DSM-V), American Psychiatric Association; Dr. Anand Pandya, MD NAMI

Class 2: Handout # 4
Symptoms of Psychosis

Delusions:

These are disturbances in thought involving the misinterpretation of perceptions or experience. These beliefs usually have a theme of persecution (being tricked, spied upon, subjected to ridicule). They can also involve religious themes and feelings of being cosmically important. Delusional thinking represents a "gross impairment in reality testing, which grossly interferes with the capacity to meet the ordinary demands of life."

- In Major Depressive Disorder, delusions commonly involve obsession of guilt, sinfulness, poverty, feelings of persecution and extreme hypochondria; these are referred to as "mood congruent" psychotic features. Delusions may also be "mood incongruent" meaning that they have nothing to do with what would be expected from someone in a depressed state.
- In bipolar illness, delusions are often grandiose and frequently religious, with voices (auditory hallucinations) perceived as commands from God. As with Major Depressive Disorder, these psychotic features may be "mood congruent" or "mood incongruent."
- In schizophrenia, delusions can be bizarre and tend to persist for long periods of time if left untreated. The longer that the delusion goes untreated, the less likely it is to respond to medications.

Hallucinations:

Most commonly, hallucinations involve hearing one or several voices. The voices are perceived as distinct from the person's own thoughts, and are often experienced as critical and threatening. Hallucinations can also occur in the other senses (seeing, smelling, taste and touch), and are generally experienced without insight into their pathological nature.

Disorganized speech:

This is totally illogical thinking or "formal thought disorder" as evidenced in the person's speech. The individual may "slip off the track" (derailment), answers to questions may be totally unrelated (tangential) or even severely disorganized (incoherence, "word salad," "loosening of associations"). Often the thought itself is lost and cannot be retrieved (thought blocking).

One of the most common forms of disorganized speech is perseveration. This refers to a person "getting stuck" on a theme or topic and returning to that topic over and over.

Grossly disorganized or catatonic behavior:

Disorganized behavior ranges from childlike silliness and inappropriate reactions, to totally unpredictable agitation. There are problems in goal directed behavior and great difficulties in performing the activities of daily living. Behavior is often bizarrely disturbed (posturing, grimacing), appearance markedly disheveled, with frequent

untriggered agitation, particularly swearing, shouting and negativism (refusal to accede to requests). Some posturing, grimacing, rocking, pacing and involuntary movements may be a side effect of medications. If these behaviors do not begin until after medication is started, it is important to inform the treating physician immediately. Catatonic motor behaviors involve a marked decrease in reactivity to the environment (stupor, muteness, rigidity), or excessive, purposeless motor activity (catatonic excitement).

Although catatonia is rare in general, about half of all cases of catatonia occur in mood disorders.

NOTE: It is estimated that 50 percent of cases of catatonia occur in mania and psychotic depression.

Sources: Diagnostic and Statistical Manual (DSM-V), American Psychiatric Association
Dr. Anand Pandya, MD NAMI

Class 2: Handout # 5
Overview of Major Depressive Disorder and Bipolar Disorder

- Bipolar disorder (type I or type II) occurs in approximately 1 percent of the world population, and about 2 percent of the U.S. population. Although bipolar disorder may begin in childhood, the median age of onset is 25, according to the National Institute of Mental Health (NIMH). The rates of major depressive disorder are dramatically higher: 1 man in 10, and 1 woman in 5 will have a serious depression in their lives, usually before they are 40 years old.

- The mood disorders are typically episodic (recurrent). Twenty percent of individuals with Major Depressive Disorder have only one episode. But in more than half of all cases of Major Depressive Disorder, the illness returns within 2 years. In these recurrent affective disorders, the average number of episodes of depression in a lifetime is about seven; for bipolar disorder, about 11.

- Suicide is a high risk for people with these disorders. Tragically, 15 percent of those individuals suffering from recurrent depressive disorders kill themselves. This is a suicide rate 30 times greater than that of the general population. According to the Centers for Disease control (CDC), some racial and ethnic minorities are more likely to have Major Depressive Disorder and less likely to receive appropriate treatment than Caucasians.

- The rates stated above reflect the striking gender differences in the incidence of depression, with women outnumbering men by 2 to 1. In men, the rate of depression peaks at age 55-70, and the highest rates of suicide in any age category occur in white males over the age of 69.

- Minorities tend to present more somatic symptoms, unexplained aches and pains. The experience and expression of depression varies across cultures. Feelings of guilt, despair, self-deprecation and suicidal ideas are often rare or absent among non-white populations. Somatic and quasi-somatic symptoms including changes in sleep patterns and appetite, energy, body sensation and motor function are more common.

Class 2: Handout # 6
Symptoms Checklist of Major Depressive Episodes and Manic Episodes

Descriptive Categories	Major Depressive Episode	Manic Episode
Mood "Affect"	☐ Depressed, sad or very irritable; cannot be cheered up; **(dysphoria)** ☐ Loss of interest and pleasure in daily activities **(anhedonia)**	☐ Abnormally elevated mood, expansive emotions (broad, dramatic), high **(euphoria)** ☐ Irritable, critical, argumentative, stubborn
Physical (body) Symptoms	☐ Insomnia or sleeping too much ☐ Change in appetite or a significant unintentional change in weight ☐ Being visibly slowed down or agitated ☐ Extreme fatigue and lack of energy ☐ Decreased sexual drive ☐ Catatonia (psychotic stage)	☐ Decreased need for sleep ☐ Insomnia, stays up all night ☐ Increased appetite ☐ Sudden weight loss ☐ Increased sexual drive (often to the point of hypersexuality) ☐ Catatonia (psychotic stage)
Behavior	☐ Decreased motivation ☐ Decreased task performance ☐ Withdrawal and isolation ☐ Loss of gratification in effort ☐ Lack of attention to hygiene and appearance ☐ No desire to talk, interact, socialize ☐ Grossly disorganized (psychotic stage)	☐ Impulsive ☐ Intrusive, uninhibited ☐ Increased goal setting and creativity ☐ Disorganized, easily distracted ☐ Recklessness; spending money, bad business investments, sexua misadventures ☐ No concern about consequences of behavior
Thinking	☐ Accusatory, self-blaming thoughts ☐ Feelings of worthlessness or excessive guilt ☐ Having very low self-esteem ☐ Marked indecisiveness or the inability to think, remember, concentrate ☐ Recurrent thoughts of death, suicidal thoughts, suicidal plans ☐ Delusions (psychotic stage) ☐ Disorganized , incoherent speech (psychotic stage)	☐ Inflated self-concepts of power, greatness, importance (grandiosity) ☐ Pressured speech ☐ Racing thoughts (flight of ideas) ☐ Rapid shifts of attention ☐ Poor concentration ☐ Memory distortion ☐ Delusions (psychotic stage) ☐ Disorganized, incoherent speech (psychotic stage)
Senses	☐ Hypersensitive to noise, light, stress ☐ Hallucinations (psychotic stage)	☐ Lack of sensitivity to heat, cold, hunger, thirst, pain, injury ☐ Seeks over-stimulation ☐ Hallucinations (psychotic stage)

Sources: Diagnostic and Statistical Manual (DSM-V), American Psychiatric Association
Dr. Anand Pandya, MD NAMI

Class 2: Handout # 8
Criteria for a Manic Episode

Mood:

1. Abnormally elevated, expansive, euphoric (high) and/or irritable mood for at least one week (or less if hospitalization is necessary).

   During that period there must be a marked decline in functioning and at least 3 more symptoms from the list below (must have at least 4 more symptoms if the mood is only irritable).

Body:

2. Decreased need for sleep; insomnia; staying up all night.

Behavior:

3. Increase in goal-directed activity (can include excessive planning of an activity); psychomotor agitation.

4. Increase in pleasurable activities that risk painful consequences (excessive spending, sexual recklessness, foolish business investments).

Thinking:

5. Inflated self-esteem or grandiosity.

6. More talkative than normal or pressure to keep talking (pressured speech)

7. Rapid thoughts or "flight of ideas."

8. Distractibility; short attention span, difficulty concentrating.

The criteria for Hypomania is the same as mania except:

- The episode can last as few as 4 days

- There is an obvious change, but not a marked impairment in functioning

Class 2: Handout # 9
How Can We Sort Out Myths from Fact?

Because of the bizarre and frightening aspects of behavior manifested in the major mental illnesses, many myths exist—including that people with mental illness are all dangerous, or they are "psychopathic" killers (a common confusion with the term "psychotic"). None of this is true. Let's look at some facts:

- People with schizophrenia and mania who take medication regularly and who do not abuse alcohol or other drugs are no more violent than the rest of the population. In fact, most people with schizophrenia are customarily withdrawn, frightened and passive.

- Similar to the general population, people with untreated schizophrenia and mania are more liable to commit a violent act if they are on street drugs (crack, meth, cocaine, speed, PCP – even marijuana) or if they are abusing alcohol. The use of street drugs or alcohol increases the likelihood that the untreated individual may act on the violent thoughts and paranoid delusions they are having. The combination of major mental illness and substance abuse is a significant predictor of aggressive behavior.

- The likelihood of violence is greatest among males in their late teens or early 20's.

- The best prediction of future behavior is past behavior. There is good reason to be wary of an individual who was aggressive before becoming ill, or of individuals who have previously been violent when they were particularly disturbed. If your relative has never been aggressive, or never aggressive in a period of psychosis, it is unlikely that s/he will become so.

- Warning signs of imminent physical violence that inpatient staff in psychiatric facilities are taught to look for are: impulsivity, talking more about violent ideas, a sudden change in eye contact (staring or avoiding looking others in the eye), pacing, becoming visibly angry, yelling, tremors, a rigid posture, clenching jaws and fists, pulsing arteries in the temples, verbal abuse, profanity, and hyperactivity.

- Besides our concern about aggression, we all deal with our dread that our family members will do something harmful to themselves. Some people, especially those with more insight into the damage caused by their illness, may become depressed after a psychotic or manic episode. Many families struggle through the active phase of schizophrenia or intense mood episodes only to be stunned by a family member's suicide attempt when they felt that things were getting better. Even if these critical events don't happen in our experience, it is important to know about them. As we say in NAMI, "We never know when another family will desperately need what we know."

CRISIS FILE

Mental Health and Crisis Services in _____ County

This page must be specifically prepared for each course location and included in the Crisis File (Number page at the bottom: Crisis File – 1)

Crisis team number _____

Local mental health agency number _____

Local mental health caseworker services number _____

Local hospital number _____

Local police number _____

State police number _____

Any other information you feel would be of benefit.

Other:

NAMI State Organization number _____

NAMI Affiliate office number _____

Local Support Group Facilitator's # _____

State Department of Mental Health # _____

The Crisis

Sooner or later, if a family member is diagnosed with schizophrenia or a major mood disorder, it is likely that some sort of crisis will occur. When this happens, there are some actions which you can take to help diminish or avoid the potential for disaster. Ideally, you need to reverse any escalation of the symptoms and provide immediate protection and support to the individual with mental illness.

People seldom suddenly lose total control of thoughts, feelings and behavior. Family members or close friends will generally become aware of a variety of behaviors which give rise to mounting concern: sleeplessness, ritualistic preoccupation with certain activities, suspiciousness, unpredictable outbursts, and so on.

During these early stages a full-blown crisis can sometimes be averted. Often the person has stopped taking medications. If you suspect this, try to encourage a visit to the physician. The more psychotic the patient, the less likely you are to succeed.

You must learn to trust your intuitive feelings. If you are feeling frightened or panic-stricken, the situation calls for immediate action. Remember, your primary task is to help your family regain control and keep everyone safe. Do nothing to further agitate the scene.

It may help you to know that your loved one is probably terrified by the experience of loss of control over thoughts and feelings. Furthermore, the "voices" may be giving life-threatening commands; messages may be coming from the light fixtures; the room may be filled with poisonous fumes; snakes may be crawling on the window. You have no way of knowing what they are experiencing.

Accept the fact that your loved one is in an "altered reality state." In extreme situations he or she may "act out" the hallucination, e.g., shatter the window to destroy the snakes. It is imperative that you remain calm. If you are alone, contact someone to remain with you until professional help arrives. In the meantime, the following guidelines will prove helpful:

- **Don't threaten**. This may be interpreted as a power play and increase fear or prompt assaultive behavior by the patient.

- **Don't shout**. If the mentally ill person seems not to be listening, it isn't because he or she is hard of hearing. Other "voices" are probably interfering or predominating.

- **Don't criticize**. It will only make matters worse; it can't possibly make things better.

- **Don't squabble with other family members** over "best strategies" or allocations of blame. This is no time to prove a point.

- **Don't bait your family member** into acting out wild threats; the consequences could be tragic

- **Don't stand over your family member** if he or she is seated since this may be experienced as threatening. Instead seat yourself. On the flip side, if an ill relative is getting increasingly upset and stands up, consider standing up so that if they escalate to the point of becoming more threatening, you can quickly leave the room.

- **Avoid direct, continuous eye contact or touching your family member.** Comply with requests that are neither endangering nor beyond reason. This provides the patient with an opportunity to feel somewhat "in control."

- **Don't block the doorway**. However, do keep yourself between your family member and an exit. If possible, convey calm. Although no one should feel that they need to stifle their emotions at all times in order to help an ill relative, research suggests that strong expressions of negative emotion may further destabilize individuals with mental illness.

Assistance with this section was provided by Al Horey, Western State Hospital, and Dr. Anand Pandya, MD NAMI.

In the final analysis, your family member may have to be hospitalized. Try to convince him or her to go voluntarily; avoid patronizing or authoritative statements. Explain that the hospital will provide relief from the symptoms, and that he or she will not be kept if treatment can be continued at home or outside the hospital in some other protected environment. Do not be tempted to make ultimatums such as "Either go to the hospital or leave the house." This invariably intensifies the crisis and may send the message that getting treatment is a form of punishment. It is better to discuss the behavior and the treatment as two separate results from the disease getting worse which is no one's fault. Being hospitalized often makes people feel powerless and threatened so whenever it is safe to do so, point out where your family member can make choices. For example, if there are safe alternative ways to go to the hospital, you may ask how they prefer to get there. Or if there is more than one reasonable option, ask them which hospital they would prefer.

During these crisis situations try to arrange to have at least two people present. If necessary, one should call the County-Designated Mental Health Professional while the other remains with the person in crisis.

If indicated, call the police but instruct them NOT TO BRANDISH ANY WEAPON. Explain that your relative or friend is in need of a psychiatric assessment and that you have called them for help. Tell the officer that the patient has or has not been hospitalized before, does or does not have access to any weapons. In short, try to prepare the officers for what to expect. Remember— Things always go better if you speak softly and in simple sentences.

"Long ago, when my son was little, our family had gone camping. In the middle of the night, he developed a raging fever. As we raced through the dark, unfamiliar roads of the forest looking for lights and searching for a hospital, a police station, a doctor, a telephone, I clutched his burning body. I remember feeling terrified, helpless and overwhelmed with panic. I thought that he was going to die in my arms and that there was nothing I could do to stop it. Years later, during the terrifying days of his first psychotic episode, I felt the same terror, the same helplessness, the same fear that he was dying, literally dying, in front of my eyes, and there was nothing, nothing, nothing that I could do to stop it."

- Mother of a son with schizophrenia
NAMI Washington Connections, by Eleanor Owen.

Identifying a Good Psychiatrist

Check with other families who have relatives with mental illness to see if they have had good experiences with a particular psychiatrist, one who:

- Will make special efforts to communicate with the family; can speak flawlessly in your own language.

- Will not insist on that your ill relative makes the initial contact, but rather recognizes that they may be in crisis and unable to do so;

- Will make special efforts to communicate. For instance, taking five minutes in the middle or at the end of a session to ask the patient's family in to learn their views on how things are going;

- Recognizes the illness is a no-fault brain disease

- Is strong enough not to be threatened by views of family or the individual on treatment; strong enough to discuss openly symptoms, medications and side effects, and the limits of his/her knowledge, while remaining in command of the treatment. While psychiatrists are trained to be vigilant about boundaries, any psychiatrist who communicates the idea that there is a special mystique in psychiatry that you cannot understand is not the kind of doctor we are looking for.

- Is flexible enough to experiment with treatments and to enlist families as part of the treatment team when that is indicated, e.g., as observers and reporters on the response to changes in treatment;

- Is innovative enough to consider alternative ways to engage with people who do not think they have an illness.

- Is accommodating enough to schedule visits at less frequent intervals to match the family's financial ability; communicates that he/she is more concerned about finding outcomes that satisfy the entire family than about maximizing their own income.

- Takes seriously and respects the information communicated by the family regarding the status of the patient.

Modified by Carol Howe: NAMI Threshold, Bethesda, MD

Ask the Psychiatrist:
Sample Questions

1. What is your diagnosis? What is the nature of this illness from a medical point of view?

2. What is known about how we can avoid future episodes or making this disease worse in the future?

3. How certain are you of this diagnosis? If you are not certain, what other possibilities do you consider most likely, and why?

4. Did the physical examination include a neurological exam? If so, how extensive was it, and what were the results?

5. Are there any additional tests or exams that you would recommend at this point?

6. Would you advise an independent opinion from another psychiatrist at this point?

7. What program of treatment do you think would be most helpful? How will it be helpful?

8. Will this program involve services by other specialists (i.e., neurologist, psychologist, allied health professionals)? If so, who will be responsible for coordinating these services?

9. Who will be able to answer our questions at times when you are not available?

10. What kind of therapy do you plan to use, and what will be the contribution of the psychiatrist to the overall program of treatment?

11. What do you expect this program to accomplish? About how long will it take, and how frequently will you and the other specialists be seeing the patient?

12. What will be the best evidence that the patient is responding to the program, and how soon will it be before these signs appear?

13. What do you see as the family's role in this program of treatment? In particular, how much access will the family have to the individuals who are providing the treatment?

14. If your current evaluation is a preliminary one, how soon will it be before you will be able to provide a more definite evaluation of the patient's illness?

15. What medication do you propose to use? (Ask for name and dosage level.) What is the biological effect of this medication, and what do you expect it to accomplish?

What are the risks associated with the medication? How soon will we be able to tell if the medication is effective, and how will we know?

16. Are there other medications that might be appropriate? If so, why do you prefer the one you have chosen?

17. Are you currently treating other patients with this illness? (Psychiatrists vary in their level of experience with severe or long-term mental illnesses, and it is helpful to know how involved the psychiatrist is with treatment of the kind of problem that your relative has.)

18. When are the best times, and what are the most dependable ways for getting in touch with you?

19. How do you monitor medications and what symptoms indicate that they should be raised, lowered or changed?

20. How familiar are you with the activities of the NAMI and our NAMI State Organization?

If the doctor raises the issue of confidentiality, refer to the document describing HIPAA Regulations included in the Additional Resources for this class.

Getting Satisfactory Results: Some Dos and Don'ts

Families need to know how to be effective in getting help for a person with mental illness. They need to know what questions to ask, what people to see, and where to go. They need to understand the various parts of the system and how best to interact with each part.

Frequently, when a parent, relative, or close friend becomes involved—especially during the early phases of the illness—each person is so overwhelmed by the experience that vague information and "jargon" is accepted as substantive. Families, at the time, want and need honest, direct information about the illness. They want specific, practical suggestions about how to cope during acute, as well as the stable phases of the illness. To get this kind of information, there are some things which you must do. Following are some hints to obtain positive results from "the system."

Things to Do:

1. Keep a record of everything. List names, addresses, phone numbers, etc. Nothing is unimportant. Every date, time, etc., may come in handy. Make notes of what went on during conferences. Keep all notices, letters, etc. Make copies of everything you mail. Keep a notebook or file of all contacts. Don't throw anything away.

2. Be polite. Keep all conversations to the point. Ask for specific information.

3. If your family member is 18 years of age or older, request their permission to review all documents. Many places will request written permission from the person with the illness, so consider asking your relative for this before their illness affects their ability to cooperate with signing a release of information.

4. Get the name of the physician who is coordinating the care. In some cases, you may have the right to request a different doctor who has privileges at that hospital. Get the name of the staff member on the ward who is working most closely with your family member. This is usually a psychiatric nurse, but may be a therapist, a social worker, a psychiatric resident or a case manager. Ask for an appointment to meet with this person; make it at their convenience. Come prepared with a list of specific questions. Some sample questions are:

    - "What are the specific symptoms about which you are most concerned?"

    - "What do these indicate? How are you monitoring them? Who is documenting in the chart? How often is the medication being monitored? What, specifically, is he/she getting? How much? How often? Has the patient been informed on medication side- effects? When can I look at the record book or chart? When can we meet to plan the transition back home?"

5. Keep the meeting short. If you come with a list of questions you will be able to get all the information you need in less than half an hour.

6. Write letters of appreciation when warranted; write letters of criticism when necessary. Send these to the head of the hospital (or unit—or both), and send copies to anyone else who may be involved, including the Governor. Just as there are certain actions to take in order to be effective, there are some things which tend to be counter-productive. Keep in mind that most professionals want to do a good job. Most of the direct staff (people who work directly with the patients—social workers, case managers, hospital attendants, practical nurses, doctors, nurses, therapists, etc.) are over-scheduled. Usually, there are too few staff for the number of community mental health centers, jails, etc. Thus, it is important to maintain some perspective on what one can reasonably expect.

There are, however, some specific responsibilities for which you can hold staff accountable. The following "don'ts" will help both you and the helping professionals.

- Do not come late to appointments.

- Do not accept repeated "cancellations."

- Do not make excessive demands on staff, i.e., don't harass the staff with special requests, do not have long phone conversations filled with unnecessary details, etc.

- Do not accept vague answers or statements which seem confusing. If a clinician says, "we are observing your daughter carefully," recognize that this is a statement which provides you with no information. Do not accept it without further clarification. Ask who is doing the observing, what is being observed (exactly), how is the information being documented, when can you view the progress of the observation, etc.

- Do not feel that you "should know" and therefore inhibit yourself from asking for substantive information.

- If your loved one is in a state mental hospital and you have permission to look at the record book, set up an appointment with a staff member who can review what information they have recorded. Be clear that you are not trying to find fault with their care, and that your only goal is to make sure that they have the correct and complete information about your family member.

  Ask to review your relative's Individualized Treatment Plan. This is legally mandated and must be carried out. You can ask to participate in the development of the plan. The patient has the right to have his/her wishes taken into account.

- When you ask how the staff is implementing the Treatment Plan, do not accept answers which imply that the patient is responsible for his/her own progress. Persist in finding out exactly what actions staff are taking, i.e., how often are they taking the patient for walks, which staff person is in charge of group therapy, how consistent is the treatment, i.e., does each member know what others are doing?

- Do not allow yourself to be intimidated.

- If your relative is in a group home, CCF, ICF, or any facility receiving public funds, you are entitled to inquire about personnel qualifications, etc. Do not permit unqualified personnel to continue to work without a formal complaint to the Department of Social & Health Services.

- Finally, do not be afraid or ashamed to acknowledge that you are related to a person with mental illness.

- Keep your family member informed about everything you plan to do. He/she might disapprove of your action or may wish to modify your plan.

- Finally, be assertive! As a taxpayer, you are entitled to information, respect, and courtesy. Your taxes go to public employees. You are not asking for gratuities. You are simply helping to get the job done.

Source: NAMI Washington Connections, by Eleanor Owen

Dual Diagnosis and Integrated Treatment of Mental Illness and Substance Abuse Disorder

What are dual diagnosis services?

Dual diagnosis services are treatments for people who live with co-occurring disorders—mental illness and substance abuse. Research has strongly indicated that to recover fully, a person with co-occurring disorders needs treatment for both problems—focusing on one does not ensure the other will go away. Dual diagnosis services integrate assistance for each condition, helping people recover from both in one setting, at the same time.

Dual diagnosis services include different types of assistance that go beyond standard therapy or medication: assertive outreach, job and housing assistance, family counseling, even money and relationship management. The personalized treatment is viewed as long-term and can be started at whatever stage of recovery the person is in. Positivity, hope and optimism are at the foundation of integrated treatment.

How often do people with severe mental illnesses also experience a co-occurring substance abuse problem?

There is a lack of information on the numbers of people with co-occurring disorders, but research has shown the disorders are very common. According to reports published in the Journal of the American Medical Association (JAMA):

- Roughly 50 percent of individuals with severe mental disorders are affected by substance abuse.
- Thirty-seven percent of alcohol abusers and 53 percent of drug abusers also have at least one mental illness.
- Of all people diagnosed with mental illness, 29 percent abuse either alcohol or drugs.

What are the consequences of co-occurring severe mental illness and substance abuse?

For the individual, the consequences are numerous and harsh. Persons with co-occurring disorders have a statistically greater propensity for violence, medication noncompliance and failure to respond to treatment than people living with just substance abuse or a mental illness. These problems also extend out to the families, friends and co-workers of these individuals.

Purely health-wise, simultaneously having a mental illness and a substance abuse disorder frequently leads to overall poorer functioning and a greater chance of relapse. These individuals are in and out of hospitals and treatment programs without lasting

success. People with dual diagnoses also tend to have tardive dyskinesia (TD) and physical illnesses more often than those with a single disorder, and they experience more episodes of psychosis. In addition, physicians often don't recognize the presence of substance abuse disorders and mental disorders, especially in older adults. Socially, people with mental illness often are susceptible to co-occurring disorders due to "downward drift." In other words, as a consequence of their mental illness people may find themselves living in marginal neighborhoods where drug use prevails. Having great difficulty developing social relationships, some people find themselves more easily accepted by groups whose social activity is based on drug use. Some may believe that an identity based on drug addiction is more acceptable than one based on mental illness.

Individuals with co-occurring disorders are also much more likely to be homeless or jailed. An estimated 50 percent of homeless adults with serious mental illnesses have a co-occurring substance abuse disorder. Meanwhile, 16 percent of jail and prison inmates are estimated to have severe mental and substance abuse disorders. Among detainees with mental disorders, 72 percent also have a co-occurring substance abuse disorder.

Consequences for society directly stem from the above. Just the back-and-forth treatment alone currently given to non-violent persons with dual diagnosis is costly. Moreover, individuals with violent or criminal tendencies, no matter how unfairly afflicted, are dangerous and also costly. Those with co-occurring disorders are at high risk to contract AIDS, a disease that can affect society at large. Costs rise even higher when these persons, as those with co-occurring disorders have been shown to do, cycle through healthcare and criminal justice systems again and again. Without the establishment of more integrated treatment programs, the cycle will continue.

Why is an integrated approach to treating severe mental illnesses and substance use problems so important?

Despite much research that supports its success, integrated treatment is still not made widely available to people. Those who struggle both with mental illness and substance abuse face problems of enormous proportions. Mental health services tend not to be well-prepared to deal with patients having both conditions. Often only one of the two problems is identified. If both are recognized, the individual may bounce back and forth between services for mental illness and those for substance abuse, or they may be refused treatment by one or the other system. Fragmented and uncoordinated services create a service gap for persons with co-occurring disorders.

Providing appropriate, integrated services for these individuals will not only allow for their recovery and improved overall health, but can ameliorate the effects their disorders have on family, friends and society at large. By helping these individuals stay in treatment, find housing, gain employment and develop better social skills and judgment, we can potentially begin to substantially diminish some of the most devastating societal problems: crime, HIV/AIDS, domestic violence and more.

There is much evidence that integrated treatment can be effective. For example, research shows that when individuals with dual diagnosis successfully overcome alcohol addiction, their response to treatment improves remarkably. With continued education on co-occurring disorders, hopefully, more treatments and better understanding are on the way.

Reviewed by Robert Drake, M.D.

Dealing with the Criminal Justice System

When persons with mental illness or their families are confronted with the criminal justice system, the pressure and intimidation can be overwhelming. This fact sheet offers some basic, helpful pointers. More detail can be found in the NAMI publication, A Guide to Mental Illness and the Criminal Justice System. This may be ordered online through the NAMI Store or by calling the NAMI Helpline to request a current Resource Catalog.

What should you know first about criminal law?

In criminal law, the outcome of a case depends as much on the facts of the case and the procedures followed in developing that case as it does on the actual substantive law. Individuals involved in criminal cases will be most affected by the procedural steps governing these cases from the time of arrest to the end of the case. It is, therefore, essential to have a good criminal lawyer to direct you through any encounter with the criminal justice system.

What is the difference between a misdemeanor and a felony?

Criminal violations come in two varieties, misdemeanors and felonies. There is no universal rule among the states to determine what constitutes a misdemeanor and what constitutes a felony. Generally, crimes that are punishable by incarceration of one year or less are misdemeanors, and crimes punishable by incarceration of more than one year are felonies. Beyond the maximum period of incarceration, whether a crime is a felony or a misdemeanor is significant because it will have a bearing on criminal procedures and constitutional rights.

When does an arrest take place?

An arrest occurs when the police take a person into custody in order to charge that person with a crime. To make a lawful arrest, a police officer must believe that the person to be arrested committed a crime. This is important in the context of mental illness because an arrest does not occur every time a person with mental illness is picked up or taken into custody by police.

What is booking?

Booking is the process of fingerprinting and photographing a person who has been arrested. In some instances, it may be important for the police to be notified quickly that they have a person with mental illness in custody. However, families should be cautioned that the disclosure that a person has a mental illness could make the police view the situation more seriously. Therefore, whenever possible, before family members make disclosures to the authorities concerning the psychiatric history of a mentally ill family member, they should discuss it with their attorney.

What should the family do during the interrogation?

Family members should try to prevent the police from questioning a family member with mental illness without a lawyer present. Any person who is questioned by the police and is not free to end the questioning and leave the place where he or she is being questioned must be given a Miranda warming. (The right to remain silent, etc.) The police must immediately stop questioning anyone who asks for a lawyer.

How do you find a lawyer?

Competent criminal lawyers are almost always available, even if your budget is limited. The first place to seek a lawyer if you cannot afford to pay a full fee for a private lawyer is through public defender services, court- appointed attorneys, local criminal defense lawyers' associations, or local bar associations.

The United States Constitution guarantees legal representation to every defendant in a felony criminal case. Therefore, if a defendant to a felony charge cannot afford a lawyer, the state must provide him or her with one.

What are your constitutional rights?

- The Fourth Amendment guarantees the right against unreasonable searches and seizures. Usually a warrant is required. The exclusionary rule prevents the prosecution from placing into evidence any evidence that was obtained unreasonably.

- The Fifth Amendment guarantees the right against self-incrimination, which is the well-known right to remain silent.

- The Sixth Amendment guarantees the right to a speedy trial. Every defendant in a criminal case has a constitutional right to have the charges against him or her decided quickly so that he or she can move on with life. The Sixth Amendment also guarantees the right to a public trial and a jury trial. The right to confront witnesses, a compulsory process for obtaining witnesses, and the right to assistance of counsel are also protected by this amendment.

- The Eighth Amendment protects people from cruel and unusual punishment. In addition, it protects the right to treatment for acute medical problems, including psychiatric problems.

Who decides to file charges?

The decision to file charges is often made by the police and the prosecutor's office together.

What is jail diversion?

Jail diversion is a procedure in which a person with mental illness who has been charged with a crime agrees to participate in voluntary treatment. This treatment is generally provided in the community. In exchange for participating in treatment, the charges are either dropped or deferred, pending satisfactory compliance with treatment. Jail diversion must be distinguished from probation and a suspended sentence (which are similar), which entail a conviction being entered onto the defendant's criminal record, either by guilty plea or by a verdict.

Can a person stand trial if he or she is viewed as incompetent?

No person can be tried or sentenced for a crime if -- because of a mental disease or defect -- he or she cannot understand the nature of the proceedings against him or her or assist his or her lawyer in preparing a defense. A criminal found not competent to stand trial is usually subject to civil commitment for an indefinite period.

If a person is found competent to stand trial, can he or she invoke the insanity defense?

Yes. A determination of competency does not prevent a defendant from raising the insanity defense.

Source: NAMI Web Site www.nami.org , search word "criminal justice"

A Guide to Mental Illness and the Criminal Justice System can also be found at this internet address:

http://www.nami.org/Template.cfm?Section=Issue_Spotlights&template=/ContentManagement/ContentDisplay.cfm&ContentID=60725

Suicide: What can you do to help?

Recognize signs of depression and suicide risk

- Change in personality - (such as) - sad, withdrawn, irritable, anxious, tired, indecisive, apathetic.
- Change in behavior - can't concentrate on school, work, routine tasks.
- Change in sleep pattern - oversleeping or insomnia, sometimes with early waking.
- Change in eating habits - loss of appetite and weight, or overeating.
- Loss of interest in friends, sex, hobbies, and activities previously enjoyed.
- Worry about money, illness (either real or imaginary).
- Fear of losing control, going crazy, harming self or others.
- Feelings of overwhelming guilt, shame, self-hatred.
- No hope for the future, "it will never get better, I will always feel this way."
- Drug or alcohol abuse.
- Recent loss—through death, divorce, separation, broken relationship, or loss of job, money, status, self-confidence, self-esteem.
- Loss of religious faith.
- Nightmares.
- Suicidal impulses, statements, plans; giving away favorite things; previous suicide attempts or gestures.
- Agitation, hyperactivity, restlessness may indicate masked depression,

Do not be afraid to ask: "Do you sometimes feel so bad that you think of suicide?"

Just about everyone has considered suicide, however fleetingly, at one time or another. There is no danger of "giving someone the idea," in fact, it can be a great relief if you bring the question of suicide into the open, and discuss it freely, without showing shock or disapproval. Raising the question of suicide shows you are taking the person seriously and responding to the potential of his/her distress.

If the answer is "yes, I do think of suicide," you must take it seriously.

Have you thought about how you'd do it? Do you have the means? Have you decided when you would do it? Have you ever tried suicide before? What happened then? If the person has a defined plan, if the means are easily available, if the method is a lethal one, and the time is set, the risk of suicide is very high. Your response will be geared to the urgency of the situation as you see it. Therefore, it is vital not to underestimate the danger by not asking for detail

How Can I Know if Someone is Suicidal?

Ask these questions—in the same order—to find out if the person is seriously considering suicide. Many of the answers to these questions may be upsetting; especially if your family member does not identify you or other family members as a reason to live. However it is important to reserve judgment at least initially so that you can continue to get candid answers.

1. **"Have you been feeling sad or unhappy?"**

   A "Yes response" will confirm that the person has been feeling some depression.

2. **"Do you ever feel hopeless? Does it seem as if things can never get better?"**

   Feelings of hopelessness are often associated with suicidal thoughts.

3. **"Do you have thoughts of death? Does it seem as if things can never get better?"**

   A "Yes response" indicates suicidal wishes but not necessarily suicidal plans. Many depressed people say they think they'd be better off dead and wish they'd die in their sleep or get killed in an accident, however, most of them say they have no intention of actually killing themselves.

4. **"Do you ever have any actual suicidal impulses? Do you have any urge to kill yourself?"**

   A "Yes" indicates an active desire to die. This is a more serious situation.

5. **"Do you have any actual plans to kill yourself?"**

   If the answer is "Yes," ask about their specific plans. What method have they chosen? Hanging? Jumping? Pills? A gun? Have they actually obtained the rope? What building do they plan to jump from? Although these questions may sound grotesque, they may save a life. The danger is greatest when the plans are clear and specific, when they have made actual preparations, and when the method they have chosen is clearly lethal. If the person has access to whatever they need to execute their plan, the situation is more dangerous. After you finish gathering information, one of your first tasks will be to limit access to the things that they need to complete their plan. This may mean taking away a gun or the keys to their car, or simply taking the person to the hospital where they would not be able to follow through on their plans.

6. **"When do you plan to kill yourself?"**

   If the suicide attempt is a long way off, say, in five years, the danger is less imminent. If they plan to kill themselves soon, the danger is grave.

7. **"Is there anything that would hold you back, such as the effect on a pet or someone in our family, or your religious convictions?**

   If the person says that people would be better off without them and if they have no deterrents, suicide is much more likely.

8. **"Have you ever made a suicide attempt in the past?"**

   Previous suicide attempts indicate that future attempts are more likely. Even if a previous attempt did not seem serious, the next attempt may be fatal. All suicide attempts should be taken seriously. Although some mental health professionals differentiate between "suicide attempts" (where the person intended to die) and "suicidal gestures" (where the person's primary intention was not to die but to send a message or achieve some other goal), it is important to note that suicide gestures can be more dangerous than they seem, since some people do accidentally kill themselves when attempting to only make a gesture.

9. **"Would you be willing to talk to someone or ask help if you felt desperate? Whom would you talk to?"**

   If the person who fears suicidal is cooperative and has a clear plan to reach out for help, the danger is less than if they are stubborn, secretive, hostile, and unwilling to ask for help. If they report a plan to reach out to a specific person, make sure that they have the person's telephone number and, if possible, make sure that they have discussed the fact that they have suicidal thoughts at times with the person who they identify as the one they would most likely talk to if they were desperate. If they have not felt comfortable discussing these thoughts with that individual yet, or are reluctant to raise the subject at this time, it is less likely that they will feel comfortable enough to broach the subject with that person when they are in crisis.

Source: NAMI website `www.nami.org` , search word "criminal justice"

Limit Setting

Behaviors that should not be tolerated:

Even if they are part of the illness, the following behaviors should NOT be tolerated:

- Physical abuse
- Sexual abuse
- Destruction of property (example: punching holes in walls)
- Setting fires or creating fire hazards (example: smoking in bed)
- Stealing
- Abuse of illegal and/or prescription drugs
- Severely disruptive or tyrannical behaviors (examples: walking around the house nude; blasting the stereo, intolerably loud screaming)

Allowing yourself or other members of your family to become a victim of any of these behaviors not only poses danger, but sets up an atmosphere that is extremely stressful for everyone, especially your ill relative.

Behaviors that are typical symptoms of mental illness:

A. Trying to stop any of the following behaviors in someone who is mentally ill can be like trying to stop someone with a cold from sneezing:

- Periodic departure from normal eating habits.
- Unusual sleep/wake cycles. (Example: Sleeping all day and staying up all night.)
- Delusions or disordered thinking.
- Hallucinations.
- Withdrawal to a quiet, private place.
- Some inappropriate social behavior.

B. The reasons for these behaviors are much more complicated than attempts to manipulate. They are symptoms of an illness or attempts to cope with symptoms in which manipulation may play only a small role, if any.

C. Even if a behavior is a symptom or attempt to cope with a symptom, you should not tolerate it if it is destructive or severely disruptive (see above), or if it is driving you or someone else in the house to absolute distraction.

Source: The Training and Education Center Network Mental Health Association of Southeastern Pennsylvania Philadelphia, Pennsylvania

Managing Violent and Disruptive Behavior

What you can do to manage violent or disruptive behavior:

- When you and your relative are BOTH calm, explain to him/her what kinds of behaviors you will not tolerate, as well as the specific consequences upon which you (and other family members) have decided (and agreed) for specific violent or disruptive behaviors.

  Example: "Next time you threaten to harm any of us, the police will be called."

- Get to know and recognize cues that your relative is becoming violent or disruptive. (Your own uneasiness or fear is usually a good cue.)

- Tell your relative that his/her behavior is scaring you or upsetting you. This feedback can defuse the situation, but proceed with the next suggestion if it does not. Saying you are scared does NOT mean you act scared.

- If you (and other family members) have made a limit-setting plan, now is the time to carry out the consequences. If you have not already warned your relative of the consequences when he was calm, use your judgement and past experience to decide whether to warn him/her or to just go ahead with the plan without saying anything.

- Give your relative plenty of space, both physical and emotional. Never corner a person who is agitated unless you have the ability to restrain him/her. Verbal threats or hostile remarks constitute emotional cornering and should, therefore, be avoided.

- Give yourself an easy exit, and leave the scene immediately if he/she is scaring you or becoming violent.

- Get help! Just bringing in other people, including the police if necessary, can quickly defuse the situation.

- If you or someone else has witnessed your relative recently committing or planning a violent or dangerous act, that is grounds for involuntary commitment.

What you should NOT do:

- Do NOT try to ignore violent or disruptive behavior. Ignoring only leads your relative to believe that this kind of behavior is acceptable and "repeatable."

- Do NOT give your relative what s/he wants if the way s/he is trying to get it is through bullying you. Giving in reinforces this bullying behavior and makes it likely

that s/he will use it again. Only give in if it is the ONLY way out of a dangerous situation.

- Do NOT try to lecture or reason with your relative when s/he is agitated or losing control.

- NEVER be alone with someone you fear.

  Example: Do not drive him/her to the hospital by yourself.

Source: The Training and Education Center Network, Mental Health Association of Southeastern Pennsylvania, Philadelphia, Pennsylvania

Principles to Remember when Dealing with Critical Periods in Mental Illness

1. In dealing with critical periods, it is essential to set limits on psychotic behavior and to have a plan for enforcing your ultimatum. You need to decide on the specific consequences, and you need to be prepared to back them up.

2. You must get help. No one can handle these devastating crises alone. Your plan should always involve other family members, public authorities, crisis workers, and professional assistance—notified ahead of time, if possible.

3. You must trust your instincts. If you are worried about violence or suicide, you can bet something is building up and that events are becoming overwhelming for your relative.

4. You can't keep your head in the sand about violence and suicide. You have to speak these fears directly and openly to your relative. You must show your reaction to these dangers: tell him his behavior is making you feel afraid; ask point blank if he is contemplating suicide. In crisis, candor is essential. It reduces tension, "detoxifies" secret plans, and lets a lot of air into a sealed off, turbulent mind.

5. Even though your relative is scaring you to death or making you angry, you need to approach him with respect. All good crisis intervention is calm, purposeful, and respectful.

6. Acting to protect our relatives with mental illness is the highest form of caring for them, even if it involves force or involuntary commitment. And it is a difficult paradox to deal with: to keep them safe, we must let them go, even if they hate us for "locking them up," even if they break off with us, we move decisively to ensure their well-being. We cannot hang back because we think they will no longer love us. Mental illness can put people in mortal danger. In this situation, love acts!

7. Acting to keep ourselves clear of danger is the highest form of self-care. We are really saying we have no intention of letting mental illness rob us of our life, and if that danger looms, we are ready to separate ourselves from this threat. In a much less dramatic form, this is what we learn to do, over time, to survive this illness in others.

CLASS 2

ADDITIONAL RESOURCES

Diagnostic Criteria for Schizophrenia

A. **Characteristic symptoms:** Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):

- delusions
- hallucinations
- disorganized speech (e.g., frequent derailment or incoherence)
- grossly disorganized or catatonic behavior
- negative symptoms, i.e., affective flattening, alogia or avolition

Note: Only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behavior or thoughts, or two or more voices conversing with each other.

B. **Social/occupational dysfunction**: For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).

C. **Duration:** Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. **Schizoaffective and Mood Disorder exclusion**: Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either (1) no major depressive episodes or Manic Episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.

E. **Substance/general medical condition exclusion**: The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

Source: Diagnostic and Statistical Manual (DSM-V), American Psychiatric Association

Try to Imagine What it Must be Like to Suffer from the Brain Disease Called Schizophrenia

"Schizophrenia is a disease that strikes at the very core of what makes us all human. As the cloud of schizophrenia moves across an individual's horizon, it introduces a barrier between that person and the capacity to experience warmth, to see and think clearly, and to feel and express feelings. The symptoms of schizophrenia run across the entire gamut of capacities that characterize human behavior, cognition, and emotion: perception, thought, language, emotion, volition, and creativity. The capacity to perform these functions well is often replaced by strange and terrifying internal perceptions and experiences, feelings of estrangement, the sense that personal autonomy is being violated, and the sense that control over oneself has been lost. To an outsider, these experiences are often bizarre, frightening, and off-putting. To the person with schizophrenia and his or her family, they are frightening and depressing. The combination of public misconceptions and ignorance with intense internal suffering makes schizophrenia perhaps the most tragic of human illnesses."

Nancy Andreasen, M.D., Ph.D.

Source: Schizophrenia: From Mind to Molecule.

The Vicissitudes of Schizophrenia

No single symptom is found in all individuals, nor is any one individual burdened with all the various signs and symptoms of schizophrenia. It is now believed that "Schizophrenia" is actually a group of brain diseases, each with different causes, but with similar symptomatic brain dysfunctions:

Alterations of the Senses:

Over-acuteness of perceptions: Particularly in the early part of the prodromal stage, there is a heightened sense of hearing, vivid sharpness of colors; objects tend to "shimmer" or faces are hideously transformed; stimuli flood in without any way to screen them from the senses; those afflicted are overwhelmed by everything they see and hear, they are flooded with memories from the past;

This initial hyper-sensitivity can feel euphoric at the beginning; it is often described as intensely religious, as if one is being touched by God or given sudden cosmic understanding of the universe.

Blunting of perceptions: More commonly occurs in the later stages of the illness; this is not a medication effect, but a symptomatic deadening of sensation and response described for many years before medications become available; can include blocking of feelings of physical pain.

Inability to Interpret and Respond:

Fractured, incoherent input: For many, the "broken brain" cannot properly sort incoming stimuli and synthesize these visual, auditory, emotional messages into any coherent whole; like shattering a perfectly composed picture, the individual is coping with countless "pieces" of meaning which don't fit together in any rational way; many have difficulty concentrating and cannot watch movies and TV where sight, sound, plot, etc. must be simultaneously "tracked".

Distorted input means disconnected output (thought disorder): Responses of individuals with schizophrenia appear to be random and entirely disengaged from the rational flow of expected interaction; responses are frequently inappropriate, as if the person were experiencing a completely different event. Responses appear jumbled, giving rise to a broad range of symptoms called loosening of associations, concrete thinking, impairment of logic, and word salad.

Thought blocking occurs in 95% of cases and is often interpreted by the sufferer as "someone taking thoughts out of my head" (a cardinal symptom of schizophrenia). Ambivalence is also very common, as if the person is transfixed by exact opposites and is unable to resolve them or make a decisive step one way or the other.

Delusions and Hallucinations:

Inner experience appears real: Given these vivid sensory experiences which are unmoored from any rational interpretation, delusions and hallucinations appear to form a logical and coherent pattern, and have an internal consistency; what looks "odd/bizarre" to us on the outside is perceived as totally real/true to the sufferer.

Delusions are false ideas held by the sufferer which cannot be corrected by reason: In most cases, sensory input is simply misinterpreted, often as a meaningful "signal", or it is imbued with special import. In delusions of reference, the individual believes that random events are directly related to him or her; these events are given dramatic personal significance and are integrated into complex patterns of special meaning. Another delusional belief is that one's thought are radiating out of the brain, or are being transmitted by radio or TV (thought broadcasting) or that thoughts are being put into one's brain (thought insertion). Both of these latter delusions are also cardinal symptoms of schizophrenia.

In paranoid delusions, sufferers become convinced they are being controlled by others, manipulated or "wired" in the brain by sinister forces; or they fear people are going to hurt and attack them. These fears are then "confirmed" by misinterpreting other cues. This closed system creates a self-fulfilling prophecy, which in turn serves to validate delusional beliefs.

Grandiose delusions are common -- that individuals control the weather, the movement of planets, or that they are God, Jesus, the Virgin Mary or some exalted or important person. People may believe they can fly, or that they are immune from harm, and they act on these beliefs with predictably tragic consequences.

Hallucinations are the result of over-acute senses: Visual brightness and gross distortions of visual stimuli are common. In true hallucinations, the individual sees and talks to things which are not there at all. In this case, the brain "makes up what it hears, sees, feels, smells or tastes." These phenomena are entirely real to the person. Auditory hallucinations are by far the most common in schizophrenia and stand alone as a symptom most characteristic of the illness.

Voices occur most frequently when going to sleep; in the majority of cases, the voices are unpleasant, accusatory, and critical. Although less common, smell, touch and taste hallucinations do occur and are vividly experienced.

Distorted perceptions of body parts as being detached, of body disfigurement, of one's body merging with another body, of being outside one's body are familiar hallucinations which create an altered sense of self in schizophrenia.

Changes in Emotions (affect):

Early stage depression and mood fluctuation: Many who develop schizophrenia have a clearly defined episode of depression, crying, and despondency which at the time seems inexplicable to them; this period of depression can fluctuate with moods of euphoria, feelings of religious ecstasy, recriminations of guilt and pervasive fear.

Inability to empathize: Individuals in the grip of exaggerated feelings lose the capacity to assess the emotional state of someone else; this impaired ability to "read" emotions in others is a primary reason why many people with schizophrenia have trouble with social communications and forming friendships.

Shift from exaggerated feelings to lack of feeling (flat affect): By the time the illness is full blown, many sufferers lose the capacity to feel altogether. This emotional "dullness" may cause inappropriate emotional responses to a given situation; it more commonly involves the flattening or "blunting" of the whole range of emotional feeling -- as if the emotions did not exist at all, or they can no longer be expressed. With this emotional "blankness" comes apathy, lack of drive, poverty of thought and speech

(negative symptoms). Again, this is not a medication effect; negative symptoms are products of the disease process itself.

Changes in Behavior:

Changes in motor responses: Individuals feel they are "speeded up" or slowed down; awkwardness, clumsiness, stumbling is common; many show a significant decrease in spontaneity of movement, or they are troubled by uncontrollable tics and tremors.

Need for withdrawal from others: Getting away from people, remaining quiet for long periods of time, even becoming immobile, are customary ways that people with schizophrenia seclude themselves from over-stimulation. Catatonia and mutism are extreme versions of withdrawal.

Adoption of eccentric behaviors: Ritualistic movement patterns, bizarre gestures and body positions, obsessions and compulsions, parroting what others are saying (echolalia) and socially inappropriate behaviors all seem internally logical and meaningful to the sufferer, but very odd to the outside observer.

Lack of insight: The afflicted person is often not aware of the malfunctioning of his or her brain; the delusional systems appear to "explain" everything that is happening to them. People who are outside these subjectively "logical" experiences are often perceived as the ones who are disturbed because they cannot interpret these special events the way the sufferer does. Lack of insight is almost universal in this brain disease and in some cases persists for the entire duration of the illness.

"Imagine what it would be like to have the alterations of the senses, the inability to interpret incoming stimuli, the delusions and hallucinations, changes in bodily boundaries, emotions and movements that are described above. Imagine what it would be like to no longer be able to trust your brain when it told you something. . . Is it any wonder that people with this disease get depressed? Is it any wonder that they frequently feel humiliated by their own behavior? If a worse disease than schizophrenia exists, it has not come to light. . . Given the disordered brain function as a starting point, many persons with schizophrenia are heroic in their attempts to keep a mental equilibrium. And the proper response of those who care about the unfortunate persons with this disease is patience and understanding."

Impaired Awareness of Illness: Anosognosia

Treatment Advocacy Center Briefing Paper

Summary: Impaired awareness of illness (anosognosia) is a major problem because it is the single largest reason why individuals with schizophrenia and bipolar disorder do not take their medications. It is caused by damage to specific parts of the brain, especially the right hemisphere. It affects approximately 50 percent of individuals with schizophrenia and 40 percent of individuals with bipolar disorder. When taking medications, awareness of illness improves in some patients.

Impaired awareness of illness is a strange thing. It is difficult to understand how a person who is sick would not know it. Impaired awareness of illness is very difficult for other people to comprehend. To other people, a person's psychiatric symptoms seem so obvious that it's hard to believe the person is not aware he/she is ill. Oliver Sacks, in his book The Man Who Mistook His Wife for a Hat, noted this problem:

It is not only difficult, it is impossible for patients with certain right- hemisphere syndromes to know their own problems ...And it is singularly difficult, for even the most sensitive observer, to picture the inner state, the 'situation' of such patients, for this is almost unimaginably remote from anything he himself has ever known.

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What is impaired awareness of illness?

Impaired awareness of illness means that the person does not recognize that he/she is sick. The person believes that their delusions are real (e.g. the woman across the street really is being paid by the CIA to spy on him/her) and that their hallucinations are real (e.g. the voices really are instructions being sent by the President). Impaired awareness of illness is the same thing as lack of insight. The term used by neurologists for impaired awareness of illness is anosognosia, which comes from the Greek word for disease (nosos) and knowledge (gnosis). It literally means "to not know a disease."

How big a problem is it?

Many studies of individuals with schizophrenia report that approximately half of them have moderate or severe impairment in their awareness of illness. Studies of bipolar disorder suggest that approximately 40 percent of individuals with this disease also have impaired awareness of illness. This is especially true if the person with bipolar disorder also has delusions and/or hallucinations.

Is this a new problem? I've never heard of it before.

Impaired awareness of illness in individuals with psychiatric disorders has been known for hundreds of years. In 1604 in his play "The Honest Whore," playwright Thomas

Dekker has a character say: "That proves you mad because you know it not." Among neurologists unawareness of illness is well known since it also occurs in some individuals with strokes, brain tumors, Alzheimer's disease, and Huntington's disease. The term anosognosia was first used by a French neurologist in 1914. However in psychiatry impaired awareness of illness has only become widely discussed since the late 1980s.

Is impaired awareness of illness the same thing as denial of illness?

No. Denial is a psychological mechanism which we all use, more or less. Impaired awareness of illness, on the other hand, has a biological basis and is caused by damage to the brain, especially the right brain hemisphere. The specific brain areas which appear to be most involved are the frontal lobe and part of the parietal lobe.

Can a person be partially aware of their illness?

Yes. Impaired awareness of illness is a relative, not an absolute problem. Some individuals may also fluctuate over time in their awareness, being more aware when they are in remission but losing the awareness when they relapse.

Are there ways to improve a person's awareness of their illness?

Studies suggest that approximately one-third of individuals with schizophrenia improve in awareness of their illness when they take antipsychotic medication. Studies also suggest that a larger percentage of individuals with bipolar disorder improve on medication.

Why is impaired awareness of illness important in schizophrenia and bipolar disorder?

Impaired awareness of illness is the single biggest reason why individuals with schizophrenia and bipolar disorder do not take medication. They do not believe they are sick, so why should they? Without medication, the person's symptoms become worse. This often makes them more vulnerable to being victimized and committing suicide. It also often leads to rehospitalization, homelessness, being incarcerated in jail or prison, and violent acts against others because of the untreated symptoms.

Source: www.treatmentadvocacycenter.org

"David's Story"

An Excerpt from Private Terror/Public Life
by James M. Glass

It's like all my cells are exploded over the universe, and I live in each of those millions and millions of nuclei shooting in every direction. In the midst of all this, how could I possibly deal with the concrete, even tie my shoelaces, much less find my shoes?

I convinced myself several things were happening: Unrecognizable voices invaded my ears; transmitters had been planted in the ceiling; everyone on the Hall spoke about me; my behavior was watched and discussed by staff; nursing reports, patients' journals, were filled with hundreds of pages describing my appearance and movements; spies were sent into the Hall exclusively to keep track of me and to report any suspicious behavior to the hospital administration; therapists ignored their own patients and spent hours in endless discussion, looking at the ramifications of my case; TV cameras, hooked into the walls taped my facial expressions; every morning, around 3 a.m., three thousand spotlights aimed directly into my eyes; staff prepared elaborate strategies to humiliate me, to expose me and leave me naked in front of the Hall; killers hid behind closed doors and waited until night to sneak into my room; food poisoned my insides and rotted out my intestines. Lying down, my body became so brittle I felt it cracking into a thousand pieces; at night, my roommate fed on my blood. Not exactly sane thoughts. In my frame of mind, if I were to stay alive, I had to be attuned to every movement on the Hall.

I hear this voice sometimes. I call it the "maelstrom of manufactured criticism" because it always tears away at me, rips my identity into shreds, and slices away at everything I am. It's like being in the midst of the Straits of the Sirens with a ferocious storm overhead, no sun, just black clouds that turn the world into night. Sometimes the voice booms in my ears. Other times, it sounds like a song, a melody, but the lyrics, even though the singing is sweet, are filled with criticism and attack. The verbal abuse never lets up. It goes on and on for hours. Nothing outside touches me when it's there: I refuse to talk to anyone; I sit, stare, smoke cigarettes until the voice leaves.

Nothing really stops the madness. I rarely change clothes; hygiene and meals become too much. And I have more important things to do than be bothered with my nutrition or cleanliness. Contact with people seems closed off; I lose interest in what happens on the Hall. I forget what day it is; I lose track of mealtimes and Hall meetings. Something as simple as selecting a shirt paralyzes me. That's what begins my psychotic episodes, little things, nothing more dramatic than trying to find a shirt. It's like this huge problem overtakes you: moving toward the closet, opening the door, searching through the rack. Each step of the process is like climbing Mount Everest, so you say to yourself, "Why bother, let it be, stay with the one on your back." Little things are magnified a thousand times, and what happens inside your mind takes on much greater importance than your own hygiene or appearance.

Women and Depression

Clinical depression affects two to three times as many women as men, both in the U.S. and in many societies around the world. It is estimated that one out of every eight women will suffer from clinical depression in her lifetime. Women also experience higher rates of seasonal affective disorder and dysthymia (chronic depression) than men. While the rate of bipolar disorder (manic depression) is similar in men and women, women have higher rates of the depressed phase of manic depression and women are three times more likely to experience rapid-cycling bipolar disorder.

What causes the higher rate of depression in women?

The explanation for the gender gap in susceptibility to depression most probably lies in a combination of biological, genetic, psychological, and social factors.

Biological factors: There appear to be important links between mood changes and reproductive health events. Gender differences in rates of depression emerge when females enter puberty and remain high throughout the childbearing years and into late middle age. Hormonal factors seem to play a role in some of the mood disturbance experienced by women. Twenty to 40 percent of menstruating women experience premenstrual mood and behavioral changes. Approximately 2 to 10 percent of women experience Premenstrual Dysphoric Disorder, a severe form of premenstrual syndrome that is characterized by severely impairing behavior and mood changes. As many as 10 percent to 15 percent of women experience a clinical depression during pregnancy or after the birth of a baby. There also appears to be an increase in depression during the perimenopausal period, but after menopause, this does not appear to be the case. Differences in thyroid function between men and women may also contribute to the gender difference in the prevalence of mood disorders.

Another biological factor that may contribute to gender differences in depression can be linked to circadian rhythm patterns, the complex system that regulates sleep and activity over each 24- hour period. Depressed women report more hypersomnia (excessive sleeping) than do men. Gender differences in the activity of neurotransmitters including serotonin and the effects of estrogen on theses neurotransmitters may also be linked to the gender disparity in rates of depression.

Genetic factors: Some forms of depression run in families. There is a 25 percent rate of depression in the first-degree relatives (mother, father, siblings) of people with depress-ion and greater prevalence of the illness in first-degree and second-degree female relatives. But depression also occurs in people who have no family history of the disease. The genetic contribution to risk for depression is not something specific to women. Men and women from families with depression are both at greater risk than those who come from families with no depression.

Psychosocial factors: Psychosocial factors that may contribute to women's increased vulnerability to depression include the stress of multiple work and family responsibilities, sexual and physical abuse, sexual discrimination, lack of social supports, traumatic life experiences, and poverty.

Psychological make-up plays an important role in one's vulnerability to depression as well. Thus, individuals with low self-esteem, pessimistic views, and tendencies towards stress are prone to clinical depression.

Studies also indicate that sexual and physical abuse are major risk factors for depression. Women are twice as likely as men to have experienced sexual abuse. A recent study found that three out of five of the women diagnosed with depressive illnesses had been victims of abuse. In one major study, 100 percent of women who had experienced severe childhood sexual abuse developed depression later in life.

Does pregnancy influence depression?

Although it once was thought that women experienced low rates of mental illness during pregnancy, recent research reveals that over 10% of pregnant women and approximately 15% of postpartum women experience depression. As many as 80 percent of women experience the "postpartum blues," a brief period of mood symptoms that is considered normal following childbirth. However, the related hormonal and biological changes associated with pregnancy or giving birth may initiate a clinical depression. Or, the changes in lifestyle associated with caring for a young infant may constitute a set of stressors that have mental health consequences for the mother. There is a three-fold increase in risk for depression during or following a pregnancy among women with a history of mood disorders. Once a woman has experienced a postpartum depression, her risk of having another reaches 70 percent.

One woman in a thousand experiences a postpartum psychosis-a medical emergency in which the woman may inflict harm upon herself and/or her baby. The first episode of bipolar disorder in women frequently occurs following the birth of a child.

Source: NAMI Fact Sheet on Depression. This link will take you to the page on the NAMI Web site to the new NAMI Women and Depression brochure.
http://www.nami.org/Content/ContentGroups/Helpline1/FINALWomensDepressionBrochure.pdf

Criteria for Major Depressive Episode: DSM 5

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

Note: Do not include symptoms that are clearly due to a general medical condition, or mood-incongruent delusions or hallucinations.

- Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: In children and adolescents, can be irritable mood.
- Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others).
- Significant weight loss when not dieting or weight gain (e.g., a change of more than 5 percent of body weight in a month), or decrease or increase in appetite nearly every day. Note: In children, consider failure to make expected weight gains.
- Insomnia or hypersomnia nearly every day.
- Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
- Fatigue or loss of energy nearly every day.
- Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
- Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
- Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

B. The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning.

C. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).

Source: DSM-V, American Psychiatric Association

Darkness Visible: A Personal Account of Depression

Depression is a disorder of mood, so mysteriously painful and elusive in the way it becomes known to the self—to the mediating intellect—as to verge close to being beyond description. It thus remains nearly incomprehensible to those who have not experienced it in its extreme mode, although the gloom, 'the blues' which people go through occasionally and associate with the general hassle of everyday existence are of such prevalence that they do give many individuals a hint of the illness in its catastrophic form. But at the time of which I write I had descended far past those familiar, manageable doldrums…

It was not really alarming at first, since the change was subtle, but I did notice that my surroundings took on a different tone at certain times: the shadows of nightfall seemed more somber, my mornings were less buoyant, walks in the woods became less zestful, and there was a moment during my working hours in the late afternoon when a kind of panic and anxiety overtook me, just for a few minutes, accompanied by a visceral queasiness—such a seizure was at least slightly alarming, after all.

I felt a kind of numbness, an enervation, but more particularly an odd fragility—as if my body had actually become frail, hypersensitive and somehow disjointed and clumsy, lacking normal coordination. And soon I was in the throes of a pervasive hypochondria. Nothing felt quite right with my corporeal self; there were twitches and pains, sometimes intermittent, often seemingly constant that seemed to presage all sorts of dire infirmities. . .

It was October, and one of the unforgettable features of this stage of my disorder was the way in which my own farmhouse, my beloved home for 30 years, took on for me at that point when my spirits regularly sank to their nadir an almost palpable quality of ominousness. The fading evening light— akin to that famous 'slant of light' of Emily Dickinson's, which spoke to her of death, of chill extinction—had none of its familiar autumnal loveliness, but ensnared me in a suffocating gloom… That fall, as the disorder gradually took full possession of my system, I began to conceive that my mind itself was like one of those outmoded small town telephone exchanges, being gradually inundated by flood waters: one by one, the normal circuits began to drown, causing some of the functions of the body and nearly all of those of instinct and intellect to slowly disconnect…

What I had begun to discover is that, mysteriously and in ways that are totally remote from normal experience, the gray drizzle of horror induced by depression takes on the quality of physical pain. But it is not an immediately identifiable pain, like that of a broken limb. It may be more accurate to say that despair, owing to some evil trick played upon the sick brain by the inhabiting psyche, comes to resemble the diabolical discomfort of being imprisoned in a fiercely overheated room. And because no breeze stirs this cauldron, because there is no escape from this smothering confinement, it is entirely natural that the victim begins to think ceaselessly of oblivion.

Source: William Styron, Darkness Visible, NY: Random House

Criteria for Manic Episode: DSM 5

A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood, lasting at least 1 week (or any duration if hospitalization is necessary).

B. During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and have been present to a significant degree:

- inflated self-esteem or grandiosity
- decreased need for sleep (e.g., feels rested after only 3 hours of sleep)
- more talkative than usual or pressure to keep talking
- flight of ideas or subjective experience that thoughts are racing
- distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli)
- increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation
- excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)

C. The mood disturbance is sufficiently severe to cause marked impairment In occupational functioning or in usual social activities or relationships with others, or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features.

D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication, or other treatment) or a general medical condition (e.g., hyperthyroidism).

Note: Manic-like episodes that are clearly caused by somatic antidepressant treatment (e.g., medication, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar I Disorder.

Source: DSM-V, American Psychiatric Association

The Experience of Manic-Depressive Illness
A Personal Account

There is a particular kind of pain, elation, loneliness, and terror involved in this kind of madness. When you're high it's tremendous. The ideas and feelings are fast and frequent like shooting stars and you follow them until you find better and brighter ones. Shyness goes, the right words and gestures are suddenly there, the power to seduce and captivate others a felt certainty. There are interests found in uninteresting people. Sensuality is pervasive and the desire to seduce and be seduced irresistible.

Feelings of ease, intensity, power, wellbeing, financial omnipotence, and euphoria now pervade one's marrow. But, somewhere, this changes. The fast ideas are far too fast and there are far too many; overwhelming confusion replaces clarity. Memory goes. Humor and absorption on friends' faces are replaced by fear and concern.

Everything previously moving with the grain is now against—you are irritable, angry, frightened, uncontrollable, and enmeshed totally in the blackest caves of the mind. You never knew those caves were there. It will never end.

Madness carves its own reality. It goes on and on and finally there are only others' recollections of your behavior—your bizarre, frenetic, aimless behaviors—for mania has at least some grace in partially obliterating memories. What then, after the medications, psychiatrist, despair, depression and overdose? All those incredible feelings to sort through. Who is being too polite to say what? Who knows what? What did I do? Why? And most hauntingly, when will it happen again? Then, too, are the annoyances—medicine to take, resent, forget, take resent, and forget, but always to take. Credit cards revoked, bounced checks to cover, explanations due at work, apologies to make, intermittent memories of vague men (what did I do?), friendships gone or drained, a ruined marriage. And always, when will it happen again? Which of my feelings are real? Which of the me's is me? The wild, impulsive, chaotic, energetic, and crazy one? Or the shy, withdrawn, desperate, suicidal, doomed, and tired one? Probably a bit of both, hopefully much that is neither. Virginia Woolf, in her dives and climbs, said it all: "How far do our feelings take their color from the dive underground? I mean, what is the reality of any feeling?"

Source: Frederick K. Goodwin, M.D., and Kay Redfield Jamison, Ph.D., Manic- Depressive Illness. NY: Oxford University Press.

Disparities in Mental Health Treatment among GLBT Populations

National Alliance on Mental Illness

The history of mental health treatment of gay, lesbian, bisexual, and transgender (GLBT) populations is an uneasy one. In the 1950s and 60s, many psychiatrists believed that homosexuality (as well as bisexuality) was a mental disorder. Gay men and lesbians were often subjected to treatment against their will, including forced hospitalizations, aversion therapy, and electroshock therapy.

Fortunately, there have been great strides made in the nearly 35 years since the American Psychiatric Association removed homosexuality from the *Diagnostic and Statistical Manual of Mental Disorders*, or the DSM. Despite this, there are still disparities and unequal treatment among some GLBT groups seeking care.

Mental Health Treatment and GLBT Populations

In the past 35 years, the attitudes of mental health professionals have shown a positive change toward GLBT populations. For example, a 2005 study found that **58% of psychologists supported a gay-affirmative stance in therapy,** compared to only 5% in 1991.[1]

Despite these positive changes in attitudes, however, many mental health professionals still report a lack of focus on GLBT issues in their training. For example, a survey of therapists-to-be found that **even though they had positive attitudes about GLB populations, they generally felt unprepared to counsel GLB clients**, and many programs lacked coursework or training modules on GLB issues.[2]

Nevertheless, recent studies suggest that gay, lesbian, and bisexual populations are actually more likely to report using therapy or counseling than heterosexual groups.[3] Upon reflection, this is not so surprising given the stressors that GLBT groups must confront, such as homophobia, societal discrimination and prejudice, coming out, and negotiating family relationships.

There are still disparities, though, in both mental health research and services when it comes to certain GLBT populations, including:

- Racial and ethnic minorities
- Rural populations
- Bisexual people
- Transgender people
- People with serious mental illness

Racial and ethnic minorities

To date, most research on GLBT populations has been done with predominantly white samples. The mental health issues and needs of GLBT persons of color, therefore, are still largely unknown and vastly understudied.[4,5]

What we **do** know, however, is that GLBT African American, Latino, Native American, Asian Pacific Islander, and other racial and ethnic minorities share at least one thing: **they must confront racism as well as homophobia.** These multiple levels of oppression and the experience of being a minority within a minority may contribute to an increased vulnerability to mental illness, particularly depression and anxiety.[5]

In addition to these issues, there is the reality that people of color are underrepresented in mental health professions. For example, while African Americans comprise about 12% of the population, only 2% of psychologists and 4% of social workers are African American. This lack of representation in the field of mental health providers may contribute to an underutilization of mental health services among racial and ethnic minorities in general, and may also mean that for GLBT people of color seeking mental health treatment, there are even fewer culturally component resources available.

Rural populations

Not all GLBT persons live in big cities. For GLBT persons living in rural areas, there may be a number of barriers to finding GLBT-friendly mental health providers and programs.[6,7] In a study of mental health providers serving two

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rural communities, participants reported widespread anti-GLBT bias and an overall lack of resources for GLBT persons. Unfortunately, fears of harassment — or worse — prevented GLBT *providers* from working with GLBT consumers to create networks and resources.[7]

Bisexual people

Bisexual people continue to be overlooked in mental health research and may often confront stereotypes when seeking therapy or other mental health services. They may also face rejection from the larger heterosexual community as well as from gay and lesbian communities.

When working with bisexual clients, it is important for mental health professionals to recognize that for many, a bisexual identity is a legitimate identity and does not represent confusion or lack of a commitment to a gay (or straight) identity. Mental health providers should not assume that bisexuality is the presenting issue. Rather, they should take their cues from the client and proceed accordingly.[8]

Transgender people

The relationship between gender identity and the field of mental health is a complicated issue that cannot be done justice in a few paragraphs. However, too often it is the case that people who are gender-variant, or whose gender does not conform to their birth sex, face the most severe discrimination and maltreatment in *most* settings, including healthcare settings.[9]

As transgender people become more visible, it is important for providers to understand that **gender expression is not the same as sexual orientation** (transgender people often identify as straight). In addition, identifying as transgender **does not** automatically mean that someone has a mental illness.[10]

People with serious mental illness

To date, most information we have about GLBT people and mental health is related to counseling or psychotherapy. There is little to no information about gay, lesbian, bisexual, and transgender people with serious mental illness or those who require services other than therapy. What little we do know, however, suggests that GLBT people with serious mental illness are often subjected to poor treatment, particularly in the public mental health system. They often feel compelled to hide their sexual orientation in an effort to protect themselves from ridicule or maltreatment from counselors, peers, and staff.[11]

Furthermore, those agencies specifically serving GLBT populations are often uneducated or unprepared to address the needs of those who have a serious mental illness.

Those in in-patient settings have also reported that attempting to negotiate unfriendly or blatantly homophobic settings can be quite taxing. Efforts to conceal a fundamental part of themselves — their sexual orientation or gender identity — can interfere with successful treatment, as GLBT people are not able to bring the entirety of who they are into treatment.[11]

Addressing Disparities

One key way to address these disparities is through GLBT cultural competency trainings for all persons working in the mental health professions. Cultural competence involves the *individual* and his or her attitudes, behaviors, and beliefs as well as the *institution* and its behaviors and policies. Individual cultural competence means that one can communicate effectively with people who are different. At the institutional level, it means that an agency is consciously set up to meet the needs of people from different cultures. It is only through education that we can begin to dismantle the barriers to care that many GLBT persons still confront.

For more information about general standards of practice in the provision of health care to GLBT populations go to: www.glbthealth.org/CommunityStandardsofPractice.htm

Cited works: 1 Kilgore, H., Amin, K., Baca, L., Sideman, L., Bohanske, B. (2005). Psychologists' attitudes and therapeutic approaches to gay, lesbian, and bisexual issues continue to improve: An update. *Psychotherapy: Theory, Research, Practice, Training*, 42, 395-400. **2** Phillips, J.C., Fischer, A.R. (1998). Graduate students' training experiences with lesbian, gay, and bisexual clients. *The Counseling Psychologist*, 26, 712-734. **3.** Cochran, S.D., Sullivan, J.G., & Mays, V.M. (2003). Prevalence of mental disorders, psychological distress, and mental health services use among lesbian, gay, and bisexual adults in the United States. *Journal of Consulting and Clinical Psychology*, 71, 53-61. **4.** Harris, H.L., Licata, F. (2000). From fragmentation to integration: Affirming the identities of culturally diverse, mentally ill lesbians and gay men. *Journal of Gay & Lesbian Social Services*, 11, 93-103. **5** Green, B. (1994). Ethnic-minority lesbians and gay men: Mental health and treatment issues. *Journal of Consulting and Clinical Psychology*, 62, 243-251. **6.** Willging, C.E., Salvador, M., Kano, M. (2006). Pragmatic help seeking: How sexual and gender minority groups access mental health care in a rural state. *Psychiatric Services*, 57, 871-874. **7.** Willging, C.E., Salvador, M., Kano, M. (2006). Unequal treatment: Mental health care for sexual and gender minority groups in a rural state. *Psychiatric Services*, 57, 867-870. **8.** Dworkin, S. (2001). Treating the bisexual client. *Journal of Clinical Psychology*, 57, 671-680.**9.** Feinberg, L. (2001). Trans health crisis: For us it's life or death. *American Journal of Public Health*, 91, 897-900. **10.** Denny, D. (2004). Changing models of transsexualism. *Journal of Gay & Lesbian Psychotherapy*, 8, 25-40. **11.** Lucksted, A. (2004). Lesbian, gay, bisexual and transgender people receiving services in the public mental health system: Raising issues. *Journal of Gay & Lesbian*

Mental Health Issues among Gay, Lesbian, Bisexual, and Transgender (GLBT) People

National Alliance on Mental Illness

According to the National Institute on Mental Health, an estimated 26% of adults 18 and older, or 1 in 4 Americans, experience a mental illness in a given year.[1] Just like everyone else, gay, lesbian, bisexual, and transgender (GLBT) people also experience mental Illnesses.

First and foremost, however, we must remember that **being** gay, lesbian, bisexual, or transgender **is not** a mental illness in and of itself. Just because someone is GLBT doesn't automatically mean that they will experience a mental illness. According to the American Psychological Association:

"Homosexuality per se implies no impairment in judgment, stability, reliability, or general social and vocational capabilities. Further, the American Psychological Association urges all mental health professionals to take the lead in removing the stigma of mental illness that has long been associated with homosexual orientations." [2]

However, GLBT people may face unique risks to their mental health and well-being, which mental health providers should be aware of.

Most research suggests that GLBT people are likely to be at higher risk for depression, anxiety, and substance use disorders.[3-5] One study found that **GLB groups are about two-and-one-half times more likely than heterosexual men and women to have had a mental health disorder,** such as those related to mood, anxiety, or substance use, in their lifetime.[4]

In a national study comparing GLB and heterosexual groups, researchers found that gay and bisexual men were more likely to report major depression and panic disorder in the previous twelve month period. Lesbian and bisexual women were more than three times as likely to have experienced generalized anxiety disorder.[5]

The reason for these disparities is most likely related to the societal stigma and resulting prejudice and discrimination that GLBT face on a regular basis, from society at large, but also from family members, peers, co-workers and classmates.

In terms of more serious mental illnesses, such as those that are long-term and require hospitalization or in-patient care, unfortunately we don't know very much. However, of the approximately 18 million people with serious mental illness, a reasonable estimate suggests that about 720,000 are gay, lesbian, bisexual, or transgender.[6]

In one of the few studies of serious or major mental illness among GLBT people, researchers found that LGB men were less likely to report psychotic disorders, such as schizophrenia, but more likely to report mood disorders, such as depression and bi-polar disorders. They found no differences between GLBT and heterosexual women.[7]

A note on terminology

The term "GLBT" is commonly used as shorthand for the *gay, lesbian, bisexual*, and *transgender* community. It is important to note that while these groups may share some similarities, they are by no means identical in terms of their mental health issues, concerns, or needs.

While the terms *lesbian*, *gay*, and *bisexual* (and *heterosexual*) refer to someone's *sexual orientation*, ***transgender*** is a term related to gender identity, or someone's sense of being a man or woman, boy or girl. Transgender people are heterosexual, gay, lesbian, and bisexual.

The term ***gay*** typically refers to a man who is romantically and emotionally attracted to other men.

Lesbian (or gay woman) refers to a woman who is romantically and emotionally attracted to other women.

Bisexual refers to someone who is romantically and emotionally attracted to men and women. Being bisexual does not necessarily mean someone is involved in multiple relationships at once.

Some men and women may engage in same-sex behavior yet still identify as heterosexual, and some lesbian or gay people may have sexual relationships with people of the other sex. It is important not to make assumptions or judge people when it comes to sexual orientation and gender identity.

Finally, GLBT people are just as diverse as everyone else! We are old, young, rich, poor, parents, children, friends, co-workers, Latino, African American, and on and on. Just like people with mental illness, GLBT people are everywhere and in every community!

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Special Considerations

Dual or Double Stigma

Mental illness is regrettably still stigmatized in our society. So, too, is being lesbian, gay, bisexual or transgendered. A GLBT person with mental illness may be in the unfortunate position, then, of having to contend with *both* stigmas. It is often the case that GLBT people experience a mental health care system that is not comfortable with or sensitive to issues related to sexual orientation, while the GLBT community is not sensitive to or educated about serious mental health issues.[8] This societal stigma can contribute to and exacerbate existing mental health problems.

Family Support

People with mental illness often rely on family for support.
However, for some GLBT people, families are not accepting of their sexual orientation or gender identity. In extreme cases, GLBT people are disowned or kicked out of their homes, which leaves them without an important source of support. Such situations may contribute to more vulnerability among this population, and they suggest just how important it is for GLBT people to have access to affirming, supportive, and culturally appropriate mental health services.[8]

Violence

The societal stigma and prejudice against GLBT people take many forms. Too often, they can take the form of verbal or physical violence. Experiences of violence can have significant and enduring consequences for mental health. A recent study found that 25% of GB men and 20% of LB women had experienced victimization as an adult based on their sexual orientation.[9] In turn, these groups also reported more symptoms of depression, anxiety, and post-traumatic stress. Mental health providers need to be aware of this issue and the potential negative effects it can have on GLBT peoples' mental health.

Internalized Homophobia

Homophobia refers to irrational fear or hatred of gay people. Sometimes, GLBT people turn society's negative view about them inward, or *internalize* it. This can affect psychological well-being and can have consequences for healthy development, particularly among youth.[10] Again, mental health providers need to be aware of this issue and how it may affect mental health and well-being among their GLBT clients and patients.

In sum, GLBT people **do not** by definition have a mental illness, but they have to contend with societal stigma and negative experiences that likely contribute to an increased vulnerability to mental illness. It is important to note, however, that despite this, most GLBT people ultimately live happy and health lives!

Resources

GLBT National Hotline
1-888-THE-GLNH (843-4564)

Rainbow Youth Hotline
1-877-LGBT-YTH (1-877-542-8984)

LGBT Suicide Prevention Hotline
www.TheTrevorProject.org or 1-800-850-8078

NAMI
www.nami.org
1-800-950-NAMI (6264)

Parents, Families and Friends of Lesbians and Gays
www.pflag.org

American Psychological Association
www.apa.org/pi/lgbc/

Rainbow Heights Club
www.rainbowheights.org
Support and advocacy for LGBT mental health consumers (based in New

Cited References

1. www.nimh.nih.gov/healthinformation/statisticsmenu.cfm Accessed May 24th, 2007.

2. www.apa.org/pi/statemen.html Accessed May 24th, 2007.

3. Omoto, A.M, Kurtzman, H.S., (Eds.) (2006). *Sexual orientation and mental health: Examining identity and development in lesbian, gay and bisexual people.* Washington, DC: APA Books.

4. Cochran, S.D., Sullivan, J.G., & Mays, V.M. (2003). Prevalence of mental disorders, psychological distress, and mental health services use among lesbian, gay, and bisexual adults in the United States. *Journal of Consulting and Clinical Psychology*, 71, 53-61.

5. Meyer, I. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin*, 129, 674-697.

6. Laumann, E.O., Gagnon, J.H., Michael, R.T., & Michaels, S. (1994). *The social organization of sexuality: Sexual practices in the United States.* Chicago, IL: University of Chicago Press.

7. Hellman, R.E., Sudderth, L., Avery, A.A. (2002). Major mental illness in a sexual minority psychiatric sample. *Journal of the Gay and Lesbian Medical Association,* 6, 97-206.

8. Lucksted, A. (2004). Lesbian, gay, bisexual and transgender people receiving services in the public mental health system: Raising issues. *Journal of Gay & Lesbian Psychotherapy,* 8, 25-42.

9. Herek, G.M., Gillis, J.R., Cogan, J.C. (1999). Psychological sequelae of hate crime victimization among lesbian, gay, and bisexual adults. *Journal of Consulting and Clinical Psychology,* 67, 945-951.

10. Eubanks-Carter, C., Burckell, L.A., Goldfried, M.R. (2005). Enhancing therapeutic effectiveness with lesbian, gay, and bisexual clients. *Clinical Psychology:*

Double Stigma: GLBT People Living with Mental Illness

National Alliance on Mental Illness

As anyone living with mental illness can confirm, in our society there are still stigma and prejudice associated with mental illness. In fact, some people may refuse to seek professional help to avoid the stigma it might bring.[1]

As if this were not challenging enough, consider what it must be like to face mental illness as part of an additionally stigmatized group; in this case, as a gay, lesbian, bisexual, or transgender (GLBT) person. Unfortunately, this person must deal with a **double stigma.** Further, those who are living in poverty, have a disability, or are from communities of color may have multiple stigmas to contend with.

GLBT people must confront stigma and prejudice based on their sexual orientation or gender identity while also dealing with the societal bias against mental illness. The effects of this double or dual stigma can be particularly harmful, especially someone seeks treatment.

For example, some people report having to hide their sexual orientation from those in the mental health system for fear of being ridiculed, rejected, or in extreme cases, subjected to physical violence. On the other hand, when GLBT people with serious mental illness seek assistance from gay and lesbian organizations, these agencies are often not educated or knowledgeable about the full spectrum of mental illnesses and are ill-equipped to provide appropriate services.[2]

If people cannot be open and feel supported in who they are in a treatment setting, this will negatively affect their ability to benefit from the therapeutic experience. This is especially true for those confronted with double stigma.

It is important to remember, however, that double stigma is something that *society* creates. It is not the fault of the individual. To overcome stigma, we need to recognize it and work to change it. What are some of the ways that we can do this?

Providers at the Rainbow Heights Club, a Brooklyn-based program that serves GLBT people, suggest the following ways to overcome stigma:

- Think carefully about the labels applied to people, as labels can create further isolation and discrimination.
- Don't assume someone's sexual orientation or gender identity; also don't assume what their treatment needs are based on stereotypes of either GLBT people OR those living with mental illness.
- Empathize and validate GLBT persons' experiences.
- Recognize that discrimination exists for GLBT persons and can affect access to many resources.
- Work in coordination with people with mental illness rather than assuming that providers have all the answers.[4]
  (For more information: www.rainbowheights.org)

While it is imperative for society at large to dismantle stigma, many GLBT people with mental illness must still confront this double stigma in their daily lives. What are some ways to cope?

- Surround yourself with supportive people, such as family or friends or others who may be dealing with the same issues as you.
- Get appropriate treatment. Getting treatment may help you feel less isolated and to better understand your illness.
- Share your experiences with others. By breaking the silence, either about being GLBT, having a mental illness, or both, you can help people understand the issues involved with both.
- Join a political or advocacy group like NAMI. Sometimes joining forces with others to combat unjust policies or unfair treatment can be a productive way to cope with stigma.

Cited Works: 1 Corrigan, P. (2004) How stigma interferes with mental health care. *American Psychologist*, 59, 614-625. **2** Lucksted, A. (2004). Lesbian, gay, bisexual and transgender people receiving services in the public mental health system: Raising issues. *Journal of Gay & Lesbian Psychotherapy*, 8, 25-42. **3** Link, BG, Phelan, JC. Conceptualizing stigma. *Annual Review of Sociology*, Vol. 27: 363-385. **4** Rosenberg, S., Rosenberg, J., Huygen, C., & Klein, E. No need to hide: Out of the closet and mentally ill. *Best Practices in Mental Health*, 1, 72- 85.

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