@Issue: Mental health: Progress being made on many fronts, but more needs to be done

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An estimated 26.2 percent of American adults suffer from a diagnosable mental disorder in a given year. A mental illness is a “medical condition that disrupts a person’s thinking, feeling, mood, ability to relate to others and daily functioning,” says Sylvia Axelrod, executive director of NAMI New Jersey.

Maloney: Life with Joe, before and after his illness

To mark Mental Health Awareness Month, we asked Axelrod a series of questions aimed at increasing understanding of the issues facing those with mental disorders and the mental health community. Her organization is a non-profit organization “dedicated to improving the lives of individuals and families affected by mental illness” through education, support, advocacy and public awareness programs. Her remarks have been edited because of space limitations. Her full responses are available on app.com/opinion.

Overall, about how many New Jerseyans receive some sort of treatment for mental illness each year?

It is estimated that nearly 995,000 people in New Jersey aged 18 or older (14.5 percent of the adult population) received mental health treatment or counseling during the past 12 months.

Mental illnesses can affect persons of any age, race, religion or income. Mental illnesses are treatable. Most people diagnosed with a serious mental illness can experience relief from their symptoms by actively participating in an individual treatment plan.

What percentage of people could have benefited from some kind of treatment who didn’t seek it or couldn’t access it?

About 60 percent of adults and almost half of youth 8-15 with a mental illness received no treatment in the previous year.
What are the most commonly diagnosed conditions?

Serious mental illnesses include major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, posttraumatic stress disorder (PTSD) and borderline personality disorder.

Approximately 40 million American adults ages 18 and older, or about 18.1 percent of adults, in a given year have an anxiety disorder. Another 9.5 percent have a mood disorder — a major depressive disorder, dysthymic disorder or bipolar disorder. Another 4.4 percent of the American population will suffer from one of the three main types of eating disorders — anorexia nervosa, bulimia nervosa and binge-eating disorder — over the course of their lifetime.

What are the most important advances in treating mental illness over the past decade or so?

The past decade has seen steady progress in the treatment of mental illness, though no real breakthroughs. Clinicians and scientists have been able to refine and improve the way we use available drugs and therapies to optimize outcomes. However, many patients' needs remain unanswered. Treatment outcomes for most psychiatric disorders have made small, incremental steps forward without game changing breakthroughs. Schizophrenia, bipolar disorder, obsessive compulsive disorder and other mental illnesses continue to mar the lives of millions.

In the area of schizophrenia and schizoaffective disorder there has been a steady process towards re-conceptualizing these conditions as neurocognitive disorders. This suggests that cognitive deficits are the fundamental processes underlying the better-known, more obvious outward symptoms of the disease, namely, delusions and hallucinations. Consistent with this approach, new emerging interventions are based on cognitive remediation psychotherapies.

Broadly defined, cognitive remediation is the use of various techniques to guide and facilitate improvements in cognitive functioning. Various models are being tested. Some are employing computer-based cognitive remediation methods that utilize visual information centered computer games while other emphasize the processing of auditory input.

Other approaches have focused on group settings as the vehicle for improving group-based social cognition. In parallel, attempts are being made to develop an entirely new class of drugs that target cognitive impairment in schizophrenia. A few of these drugs are in advanced clinical trials.

In terms of new antipsychotic medications released in the past two decades, the progress is not clear cut. These drugs represent a mixed blessing. The newer antipsychotic drugs are a big step forward in terms of providing symptom relief with fewer movement disorder side effects, which used to be prominent with the older drugs.

On the flip side, the newer drugs have brought on an epidemic of metabolic side effects known as the metabolic syndrome, consisting of weight gain, obesity, diabetes, elevated cholesterol and hypertension. So the drugs of the past two decades have added more
medication options trading prominent movement disorder side effects for significant metabolic problems in the absence of substantial progress in overall clinical efficacy.

An important recent development is the broader recognition by the mental health clinicians that the metabolic syndrome is a serious complication that requires careful monitoring and aggressive treatment.

One area that stands out is the addition of several new injectable long-acting drugs. For decades there were only two injectable long-acting (weeks at a time) medications available for the treatment of schizophrenia. In the last decade, four additional injectable long acting drugs have been approved by the FDA. These long acting medications have proved quite helpful in addressing adherence which ultimately improves outcome.

The treatment of bipolar depression has been enriched by the addition of several new medication options. The newer drugs do not surpass the efficacy of the previous treatments but offer more choice and new alternatives. The new arrivals are an important and most welcome addition to a field that had very few options until recently. Unfortunately, the new drugs are associated with considerable side effects of their own, so no free ride here either.

New medications for the treatment of major depression (aka clinical depression) have entered the market, offering new options and more choices but the treatment of depression has not yet seen any dramatic breakthroughs in terms of new mechanisms of action, or better outcomes, including little or no improvement in rates of remission or relapse prevention.

A new experimental depression treatment has shown that it may be possible to achieve much faster and larger improvements by using drugs that alter glutamate neurotransmission as opposed to all the other antidepressants that primarily affect monoaminergic (serotonin, noradrenalin, and dopamine) neurotransmission. These findings are exciting and may herald the arrival of a new class of antidepressant drugs and the dawn of a new era in the treatment of depression.

What are the most significant shortcomings in New Jersey’s mental health system today?

New Jersey allocates considerable resources to make help available and to provide for the mentally ill. In 2006 and 2009, the national NAMI organization graded the mental health services in the U.S. The average was a D on a scale of A to F, and no state got a better grade than a B. In both years, New Jersey got a C overall grade. The 2009 breakdown for New Jersey was: health promotion and measurement, C; financing and core treatment/recovery services, C; consumer and family empowerment, B; community integration and social inclusion, D.

New Jersey offers good acute care facilities, there are intermediate care beds available and there are long-term beds available in county and state psychiatric hospitals. Like the rest of the U.S., New Jersey is closing down many long-term care state hospital beds while prisons and county jails are becoming the default mental health care provider for a large proportion of those patients.
New Jersey has a shortage of adequate housing units for the mentally ill, it has too few employment-targeting rehabilitation programs, and there is a huge need for better information sharing, and better coordination and integration of medical, psychiatric, rehabilitation and case management services. The mental health care system is fragmented, making it very hard to set standards of accountability.

**A major problem facing those with mental health issues is the lack of access to care. What is your best guess as to the percentage of people in need of mental health care who are unable to access it due to a shortage of mental health providers or lack of insurance coverage?**

Results from the 2012 National Survey on Drug Use and Health: Mental Health Findings indicate that nearly 60 percent of the respondents listed a lack of insurance coverage or affordability as the reason for not receiving mental health services.

Even those people covered by insurance may have difficulty accessing a mental health professional. Research suggests that when it comes to mental health, many plans have “phantom networks” — a list of providers purported to participate in a health plan but who do not, in fact, do so. This may be worsening. A recent survey indicated that more than 39 percent of the responding professionals planned to reduce mental health services, further exacerbating the difficulties citizens in New Jersey would have in finding practitioners offering mental health services.

The situation is even more critical for children in need of mental health services; 95 percent of pediatricians reported too few subspecialists to meet the needs of patients.

**Much has been written about the so-called “shame factor” that prevents those with mental health issues from seeking help. How significant an issue is that, and what is being done to address it?**

The shame factor is huge, though it is slightly smaller than it was 10 years ago. One problem continues to be emanate from the publication bias where national media lending notoriety and fame to individuals who commit crimes and characterize them as suffering from severe mental disorders. In doing so, the media stigmatizes the millions of individuals living and coping with mental illness. The fact is that the huge majority of people coping with mental illness do so quietly and without mention.

National cable networks and newspapers do not tell stories highlighting the courage, strength, and perseverance of the millions who struggle and cope with their mental illness every day. Those unsung heroes also carry a diagnosis of schizophrenia or bipolar disorder or obsessive compulsive disorder, but no morning news TV show will highlight how they work and laugh and dance and raise their children and provide for their families while fighting their illness.

Many people fear that they will be discriminated against because some time ago, some thousand miles away, someone with the same disorder had a tragic story that was splashed all over the news, exacerbating the prejudice and stigma. NAMI and the state are developing programs to fight stigma. They are effective and they are needed, but they have a long way...
to go. Along the way, the media must be held accountable and stop victimizing millions for
the sake of higher viewer ratings.

Congress has been debating provisions of the Helping Families in Mental Health
Crisis Act, which has been described as the most ambitious overhaul of the mental
health system in decades. What provisions of the bill do you support and which, if
any, do you oppose?

Congratulations are in order for Congressman Leonard Lance. Several provisions of his
“Excellence in Mental Health Act” bill were signed into law recently as part of the Medicare
“Doc Fix,” along with another of the law’s provisions authored by Rep. Tim Murphy that
authorizes a national Assisted Outpatient Treatment (AOT) demonstration project.

The Helping Families in Mental Health Crisis Act will bring new resources to the public
mental health system to improve access to outpatient services for adults and children,
medications, suicide prevention initiatives, veteran’s treatment programs and programs to
divert individuals from the criminal justice system into mental health treatment.

The legislation also will promote the use of evidence-based practices and expand the
categories of professionals who will be eligible for reimbursement through Medicaid. These
initiatives will promote effectiveness and, along with tele-psychiatry and primary care
physician training programs, increase the availability of mental health professionals. Family
involvement will be increased through modifications in the HIPAA and FERPA privacy
requirements.

NAMI New Jersey is concerned with proposals in the legislation that would severely hamper
the ability of certain legal advocacy groups including Disability Rights New Jersey (DRNJ) to
protect the rights and well-being of people with a mental illness. DRNJ has championed the
rights of families under HIPAA here in New Jersey as well as being the prime force behind
the Olmstead initiatives that has dramatically improved the lives of so many people living
with a mental illness.

Lastly, the bill calls for a major restructuring of the Substance Abuse and Mental Health
Service Administration (SAMSHA), a proposal of such a grand scope that it should be fully
vetted. As we know that the road to improved mental health administration has been
historically paved by unrealized best intentions.

The Helping Families Act was spurred by the Sandy Hook Elementary School
shootings, which some lawmakers say exposed a “broken system”— a shortage of
clinics, mental health professionals and resources for those with mental health
issues. Does that hold true in New Jersey?

In the face of significant revenue shortfalls, New Jersey has moved strongly to transform its
public mental health system to one that is imbued with the principals of wellness and
recovery. The state has made a credible effort to develop meaningful roles for persons living
with a mental illness as integral members of the state’s mental health workforce and
elevated their role as well as that of family members in the policy and oversight arena.
As a result of the Olmstead settlement, New Jersey has moved aggressively to develop supportive housing opportunities for people previously hospitalized in state hospitals as well as those at risk of hospitalization. The numbers of individuals in state hospitals who are eligible for discharge, yet remain hospitalized due to a lack of appropriate placements, has been cut in half and the wait for discharge has been reduced significantly.

But New Jersey continues to experience many of the legacy problems that exist in states around the country. We continue to allocate a larger portion of our mental health spending to institutional care than the majority of states. This is due in large part to the lack of sufficient intermediate care, appropriate “step down” programs and adequate programs to assertively outreach hard to engage consumers.

There continues to be a general lack of understanding of mental illness among the public and knowledge of the types of mental health resources that are available. The coordination between services is problematic, leaving too many opportunities for consumers to “become lost” in the service gaps. This problem only increases when individuals must cross systems in order to have their needs such as mental health and physical health met.

**Is the main weakness with the mental health system in New Jersey inadequate funding, poor policymaking or poor coordination of care?**

Whether it is outpatient counseling, inpatient treatment or safe affordable housing with supportive services, a waiting list for those in need of mental health care exists in every element of our mental health system. These access issues are compounded by the lack of coordination between elements as well as between the public system of care and private providers. Not only is the general public uninformed about mental health and the available resources but to a large extent the professional community is unaware of the resources that can help those who are affected by a mental illness.

**Given the critical importance of support from family and others in the management of those with mental illness, is New Jersey doing enough? What kind of support is available for families through your organization and others?**

Family members play an important role in supporting the recovery of individuals with a mental illness. Supporting families helps to minimize stress and can empower them to more effectively support treatment and recovery for the individual with a mental illness. Research shows that recovery outcomes improve if families receive information and support.

New Jersey was the first state in the nation to memorialize the crucial role played by families through the Family Support for the Families of Persons with a Serious Mental Illness Act of 1995. It calls for a state system of supports to assist families in their role as caretakers.

NAMI New Jersey fosters understanding about mental illness, confronts stigma often associated with mental disorders, advocates for public policies that benefit those affected by mental illness, and promotes research into the causes, treatment and recovery of mental health disorders.
Intensive Family Support Services (IFSS) comprise a range of professional supportive activities designed to improve the overall functioning and quality of life of families with a mentally ill relative. These support activities may include psychoeducation groups, single family consultation, respite services, family support groups, systems advocacy and referral/service linkage. Services may be delivered in the family’s home, at an agency, or at a community location convenient to the family.

New Jersey in 2010 began to phase in an involuntary outpatient commitment program, making it one of 43 states to do so. It allows for the compulsory, community-based treatment of individuals upon approval by a mental health screener and psychiatrist. About how many people have been affected by that program, and how effective has it been?

As of January there were about 230 individuals receiving Involuntary Outpatient Commitment (IOC) in six counties of New Jersey’s 21 counties since the program’s inception in the fall of 2012. The goal of AOT is to provide treatment to individuals before they require psychiatric hospitalization. Proponents of AOT laws believe they reduce psychiatric hospital admissions, homelessness and improve treatment compliance for a small subset of individuals who are unable or unwilling to participate in voluntary services.

Since the program’s implementation, most outpatient commitments have been inpatient conversion orders, in which the patient has first been hospitalized and then committed to IOC. Because of this the ability of IOC to serve as an early intervention alternative is yet to be realized.

The New Jersey IOC statute requires a program evaluation. New Jersey has contracted with Rutgers University to track data concerning how many people use IOC and for how long. Because IOC was recently implemented, data is not yet available.

Some people have cited what they believe to be restrictive HIPAA rules regarding disclosure of health information of individuals as an impediment to family members being able to help loved ones in need of it. How significant an impediment is that?

NAMI New Jersey has been surveying the family members of persons with a mental illness regularly since 1996. The misapplication of the privacy standards and since 2001 HIPAA, in particular, has been regularly identified as a primary barrier for a family’s ability to provide care for an ill family member.

Are medications available to successfully treat most forms of mental illness today? How much of a deterrent are the negative side effects of some drugs to those who would benefit from them? Where are the gaps, if any?

Analogous to medications for diabetes or hypertension or Parkinson’s disease, psychotropic drugs are remarkably effective at managing some of the most severe or disruptive symptoms of psychiatric disorders. Similar to the drugs for the medical conditions mentioned above, in the majority of cases psychotropics help manage the symptoms of the disease without curing it and without fundamentally altering their course. These medications are
highly effective in managing symptoms (e.g. insomnia, anxiety, and depression), reducing the frequency and severity of relapses and allowing individuals to function.

A not-so-small proportion of patients interrupt treatments for their psychiatric conditions due to concerns about side effects such as metabolic side effects, weight gain and sexual dysfunction. That does not negate the fact that in each diagnostic category there are 5 to 30 percent of patients who don’t tolerate available drugs due to side effects, or respond only partially or not at all to current treatments. In particular in the area of schizophrenia and Alzheimer’s disease, where the illness too often takes a chronic debilitating course there is a desperate need for new treatments. For all those patients it is hoped that the new research tool of pharmacogenomics, pharmacokinetics and epigenetics will lead to the discovery of curative treatments. There is also great hope that these formidable research tools will lead us to the kind of progress seen in cardiovascular disease, where it is hard to cure the illness but where science has brought tremendous progress towards disease prevention.

**Given the record of success with drugs, what role does psychotherapy play today? Is it less important than it may have been 20 or 30 years ago?**

In the past decade academic research has continued to accumulate data supporting the notion that newer psychotherapy methods can be quite effective across a broad spectrum of disorders. Despite that, psychotherapy treatment is out of reach for many in need. This new research evidence has strengthened the role of psychotherapy in the provision of mental health care services.

While psychoanalytically oriented psychotherapy treatments have lost ground, treatments modeled after cognitive behavioral therapy (CBT) approach are emerging as highly effective tools. Unfortunately there is a serious shortage of skilled professionals who can provide these treatments. The bottom line is that the new models of psychotherapy provide for an effective and important but underutilized treatment option whose importance has certainly not waned and is expected to increase in the future.