

MENTAL HEALTH NEWS™

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WINTER 2010

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 12 NO. 1

Schizophrenia: Current Research and Treatment

By Timothy B. Sullivan, MD
Clinical Chief – SMI
St. Vincent's Hospital Westchester

Ways of Looking at Schizophrenia

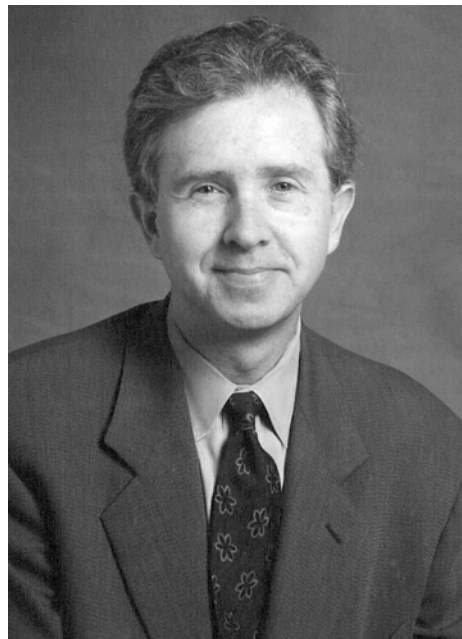
*"I was of three minds, like a tree
in which there are three blackbirds."*

Wallace Stevens,

Thirteen Ways of Looking at a Blackbird

It's an interesting time, to look back and look forward, at the state of psychiatric practice in the treatment of schizophrenia, and I find I am of at least two minds, whatever direction I look. On the one hand hopeful, grateful, and excited at progress in understanding, experience and practice; and on the other worried and frustrated, while struggling not to become cynical, as I consider how our society, and government, may respond to challenges present and expected.

I am conscious, too, that my title, and opening, may sound like a pun to some, because of the popular misunderstanding of schizophrenia as a condition of "split



Timothy B. Sullivan, MD

personality." This is, of course, a silly notion, having nothing to do with the illness, or the subjective experience of people who suffer from it, though it is re-

markable in its persistence, and in view of its roots in ignorance, fear and prejudice. There has been progress in assailing that barrier of social stigmatization, though the task has really only begun. It is another aspect of two-mindedness: to look upon the nature of schizophrenia with genuine understanding, or from within the darling mists of shame and confusion.

The term, "*schizophrenia*", was coined by Eugen Bleuler (who also first used the term, "autism," to describe some of the symptoms of the illness), a Swiss psychiatrist, in 1908, in a paper, and then in 1911 in his book, *Dementia Praecox or the Group of Schizophrenias*¹. Although a too literal translation, from the Greek, has contributed to the misconception noted above, Bleuler himself, much influenced by the work of Sigmund Freud, and keenly interested, as a philosopher as much as a clinician and scientist, in the psychological experience of the people he treated at his renowned clinic, the Burghölzli Asylum, described his use of the term differently. He thought of a specific image, that of a thick tree branch that has been struck across a stone, splaying

the end. The frayed fibers of the branch have not been lost, but they no longer cohere, and so have lost their structure, and their strength; like the cognitive functions, the thinking functions of the person affected by this illness.

The image is still poignantly compassionate, both for its evocation of the violence with which the illness often first afflicts the individual, and for its allusion to the helplessness that is prevalent, until the process of healthful change, and recovery, can begin. It was also a prescient, and clinically astute observation, for we now know that schizophrenia is most fundamentally a dysregulation of the relationships between parts of the brain that are crucial for cognitive (thinking) tasks: the ability to initiate, plan, and sequence behaviors; the ability to abstract a principle or problem-solving strategy; the ability to be cognitively flexible; to make certain decisions; to interpret social information, and generate useful social responses; and certain aspects of attention and what is called "working memory," the type of

see *Ways of Looking* on page 26

My Return From the Darkness of Schizophrenia

By Ira Minot, LMSW
Founder and Executive Director
Mental Health News

*Led From the Darkness
of Schizophrenia by Her Painting
and a Dedicated Psychiatrist
An Interview with Susan Weinreich*

Susan Weinreich is an award-winning artist whose work has won acclaim around the world. For close to 40 years she endured a heroic journey through the darkness of schizophrenia. Her story has become an inspiration to many and she has become an advocate for people with mental illness. *Mental Health News* is deeply grateful to Susan for sitting down with us and candidly sharing her incredible story with our readers.

Q: Tell us about your experience with schizophrenia.

A: I was diagnosed with paranoid schizophrenia at the age of 19. However, I did



Susan Weinreich

not learn of my diagnosis until 6 years later. The doctor who first treated me in the early 1970's when I was at college in Rhode Island believed that a patient's

diagnosis was not to be disclosed or discussed with them. Back then, schizophrenia was a very taboo word to use, and had a "death sentence" connotation attached to it. I believe my doctor felt it was not necessary to tell me, although I knew there was something killing me — emotionally and psychically — and that I was dying inside. He did not understand what was really happening to me, although I knew there was something dreadfully wrong.

I received a couple of diagnoses after that — all related to schizophrenia — from different doctors in the years that followed. One was chronic undifferentiated schizophrenia and one was schizoaffective schizophrenia. I experienced different degrees of the illness over time. When I was diagnosed with chronic undifferentiated schizophrenia, I was pretty far gone and paranoid. When I was diagnosed with schizoaffective schizophrenia, I was experiencing a mood component that had entered into the picture. As the years passed, I progressed along a continuum or spectrum of my illness and recovery. Years later, I found myself dealing with major depression, which I feel was a

result of burning out from all the stress I was under during the years that I was psychotic and trying to cope with that. It was quite a journey from psychoses to neurosis and then arriving at some semblance of normality that I have today.

Q: Once you did learn of your diagnosis, did that change how you viewed your illness, the way you felt inside, or how you viewed yourself as a person?

A: A part of me knew that who I was as a person, was more than simply a label, a diagnosis, or a clinical picture. It had to do more with my spirit and my soul, in spite of the fact that I was living in such a darkened place that my illness created in me.

Q: Do feel that you suffered a great deal more than necessary during the early years of your treatment?

A: Absolutely. My first experience in treatment during my college years did not provide me with what I would now call

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Mental Health News Upcoming Theme and Deadline Calendar

Spring 2010 Issue:

"A Look Into the World of Anxiety Disorders"
Deadline: February 1, 2010

Summer 2010 Issue:

"Addressing the Needs of Caregivers"
Deadline: May 1, 2010

Fall 2010 Issue:

"Mental Health Services
for Children and Adolescents"
Deadline: August 1, 2010

Winter 2011 Issue:

"Women's Issues in Mental Health"
Deadline: November 1, 2010

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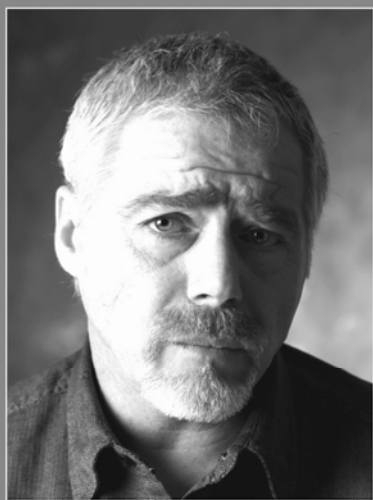
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From the Publisher

There are “No Old Topics” When it Comes to Mental Health Education

By Ira H. Minot, LMSW
Founder and Executive Director
Mental Health News

I was recently asked “Why do you keep revisiting the same old topics over again in *Mental Health News*?” I did not have a cute or definitive answer at the moment. However, as I sit here writing this column, I am convinced that it is because you can never cover a good topic often enough. Each time you do, something new and wonderful always seems to rise to the surface.

Mental Health News examined the topic of Schizophrenia back in the fall of 2005, and a remarkable thing happened when I pulled the five year old newspaper from my files and began reading through it. I came upon a most moving article called “Trapped in a Fugue: Jimmy’s Story” by Mindy Appel, ACSW, LCSW. Mindy wrote about her brother Jimmy and his tragic battle with Schizophrenia. If you haven’t read it, I urge you to go to our website at www.mhnews.org, go to the “back issues” tab on the upper toolbar, click on our fall 2005 issue, and go to page 12. I bring up this article now because it illuminates how helpless a family can become in trying to cope with a loved one who has developed a mental illness. These feelings of helplessness extend not only to the clinical management of the illness, but also to the extreme harshness brought on by the stigma towards people with mental illness. I also bring up this article because it has such personal meaning to me. You see, Mindy is a first cousin of mine, and I did not know of Jimmy’s illness until Mindy shared it with me and the readers of this publication back then in 2005—some 30 years after Jimmy was diagnosed with schizophrenia.

As I sit here writing, I think back on my childhood and realize how common it was for families back in the 1950’s to sweep emotional problems under the rug. Looking back, I never understood why I hadn’t become closer with my cousins Mindy and Jimmy. Had our family’s closely-held secrets kept us apart? Jimmy, Mindy and I were not that far apart in age, and it is as tragic and ironic that I too would fall victim to a devastating mental illness (although later in life) as Jimmy had as a young adult.



Ira H. Minot, LMSW

I knew I had to devote this column to the topic of how families and the public in general need to be continually reminded to be more open and less afraid of mental illness. I turned to the internet for inspiration and came upon a news item just recently posted entitled “Glenn Close and Family Tackle Stigma of Mental Illness.” I clicked on the link and was brought to an ABC News page with an October 21, 2009 article by Katie Escherich, entitled “Glenn Close and Family Tackle Stigma of Mental Illness: Actress Inspired by Sister Jessie Close, Nephew, to Raise Awareness.” There was also a wonderful video interview with Glenn Close and her sister Jessie moderated by George Stephanopoulos, as well as a link to a new nonprofit organization founded by Glenn Close called, Bring Change 2 Mind. I followed the link and found www.bringchange2mind.org. It’s a wonderful campaign to end stigma towards mental illness that has partnered with many noteworthy organization’s that are listed on the site. Bring Change 2 Mind features a series of videos shot at Grand Central Station by Director Ron Howard in which Glenn, her sister Jessie and others walk through the great plaza in Grand Central wearing simple white tee shirts with, in Jessie’s case, “Bipolar” written on it and with Glenn wearing one that simply has “Sister” written on it.

The slogan of Bring Change 2 Mind is “Change a Mind and Change a Life.” I know I speak for many in the mental health community in saluting this effort. Campaigns to end stigma, to increase community education, and to support increased funding for treatment and research, are essential to our efforts to improve the lives of people with mental illness. It is always such a powerful message when delivered by people of notoriety and fame. I think it’s terrific! I haven’t yet seen the Bring Change 2 Mind tee-shirt video ads appear on television here in Pennsylvania, but I hope they will, and hope they keep playing them over and over again. I believe that if they do, people will become less fearful and more educated in their attitudes toward mental illness—and that’s a good thing.

But you may say, “This is a message we’ve heard before.” and “Oh, another campaign to end stigma?” and “Didn’t you just have actor Joey Pantoliano on the front page of *Mental Health News* announcing an anti-stigma campaign he recently started called No Kidding Me 2?” The answer is YES!! But as I stated at the beginning of this column, you can never cover an important topic often enough—especially when there is so much work yet to be done. There are no “old topics” when it comes to mental health education.

I happen to love old movies and watch the Turner Classic Movie channel TCM. Robert Osborne, the primetime host of TCM once said, “I always say that I envy someone who hasn’t seen ‘Sunset Boulevard’ and is seeing it for the first time. That’s not an old movie then; that’s a new movie. I’m a little cynical about people who say they don’t like old movies. Would you not read ‘Huckleberry Finn’ or ‘David Copperfield’ because they’re old books? It’s so stupid to cut yourself off from so much pleasure.”

This issue of *Mental Health News* does cover an old topic, but I think you will find many wonderful things that rise to the surface from within its pages. Our two cover stories are a prime example.

Timothy Sullivan, MD, a leading authority on severe mental illness, gives us some wonderful insights into what he has learned about schizophrenia over the course of his many years in practice. He states that, “One of the critical things we have learned – though it is information that is unfortunately often not put into practice – is that

too much of the type of medication that is useful in decreasing agitation and hallucinations (antipsychotic medication) can make these thinking problems worse, so that the right amount of medicine, generally, is that which minimizes the side effects the medicine can cause.”

Our other cover story is our interview with Susan Weinreich, an award-winning artist, who gives us a courageous and personal look at her journey through the darkness of schizophrenia. In her triumphant return over the adversity she endured, she states, “I would say that recovery is absolutely possible and absolutely worth-while. The bottom line is that people with mental illness are no different from anyone else. As human beings we all have issues in our lives – whether they’re physical illnesses, mental illnesses, disabilities of any kind – we are all struggling to just get through it, develop, grow and face our challenges.”

This issue of *Mental Health News* has many more wonderful articles that examine the topic of schizophrenia from both a personal and scientific perspective. I wish to thank everyone for their participation.

Looking ahead in our calendar of upcoming themes, our spring issue will examine the topic, “A Look Into the World of Anxiety Disorders.” Our summer issue theme will be, “Addressing the Needs of Caregivers.” Next fall we will be discussing, “Mental Health Services for Children and Adolescents,” followed by next winter’s look at, “Women’s Issues in Mental Health.” Many of these topics were suggested by our readers, which I find to be a great way of staying on top of what’s important from your perspective.

These are difficult times for the mental health community. I sense from many of you that the economy’s severe impact on mental health budgets is one of the biggest challenges we are facing today. As the mental health community has often had to cope with lean years in the past, we can only hope that things will eventually get better. Pressing for the need for more mental health funding is certainly an old topic, but one that will always be first on my agenda at *Mental Health News*. I believe that “every day is mental health day” at *Mental Health News*. It’s a concept that will always drive this publication.

Have a wonderful winter season !



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MENTAL HEALTH NEWSDESK

Nathan Kline Institute Awarded \$10M for Schizophrenia Research Center

By Daniel C. Javitt, MD, PhD
Director, Center for Translational
Schizophrenia Research, Nathan Kline
Institute for Psychiatric Research

Nathan Kline Institute (NKI), one of the two New York State Office of Mental Health (OMH) funded research institutes in NYS, was recently awarded a 5-yr, \$10M Center grant from the National Institutes of Mental Health (NIMH) to fund establishment of a Center in Translational Schizophrenia Research. The Center is funded as part of the NIMH Conte Center program and will be administered jointly through NKI and NYU School of Medicine, its academic affiliate. The Center is directed by Dr. Daniel C. Javitt, who serves as Head of the Program in Cognitive Neuroscience and Schizophrenia at NKI and as a Professor of Psychiatry and Neuroscience at NYU. Other key personnel at NKI include Drs. Charles Schroeder, Pamela Butler, Nadine Revheim, Elisa Dias, Pejman Sehatpour, John Smiley and Peter Lakatos from the Schizophrenia Research Division; Drs. Karen Nolan, Matthew Hoptman and Leslie Citrome from the Treatment Division, Drs. Guilfoyle and Ardekani from the Center for Advanced Brain Imaging; Dr. Steven Ginsberg from the Center for Dementia Research; and Mr. Jim Robinson and Dr. Eva Petkova from the Information Sciences Division. The goal of the Center



Daniel C. Javitt, MD, PhD

is to develop improved understanding of mechanisms of brain dysfunction in schizophrenia, as well as to develop new treatment approaches for persistent negative and cognitive symptoms. In addition to NKI, the Center will involve investigators at the University of California in San Diego, Zucker Hillside Hospital in New York, and Sheba Hospital in Tel Aviv, Israel.

A primary focus of the Center is to investigate disturbances in sensory processing in schizophrenia. When schizo-

phrenia was first described by the Swiss psychiatrist Eugen Bleuler nearly 100 years ago, it was assumed that patients with schizophrenia showed normal responses to simple types of sensory input, but just interpreted the responses incorrectly. However, recent research at NKI among other locations has proven this assumption to be false. In fact, patients with chronic schizophrenia - such as those being treated at NYS OMH inpatient and outpatient facilities - perceive the world quite differently from those without the disorder. The deficits affect both auditory and visual systems and therefore serve to "disconnect" patients from their surrounding environment. Furthermore, the deficits appear to be linked to dysfunction of a specific type of brain receptor, termed the N-methyl-D-aspartate (NMDA) receptor, leading to potential new treatment approaches.

Auditory and visual dysfunction in schizophrenia

To date, deficits in sensory processing have been best established in the auditory system, which must make sense of the complex stream of sound to which we are constantly exposed. Patients with schizophrenia are not deaf. However, research at NKI among other places has shown that patients have severe deficits in detecting and interpreting sound patterns and thus hearing the "music" of sound rather than just the individual "notes." These deficits

lead to impairments in the ability of patients to function normally in complex, real-world environments and to interact normally with others.

One of the best studied disturbances in schizophrenia is a breakdown in the generation of an auditory response called the mismatch negativity (MMN). MMN is an electrical response generated by brain cells in the auditory cortex whenever there is a change in an ongoing pattern of sound such as a change in the pitch or duration of a series of repetitive tones. Whenever such a change occurs, the auditory regions of the brain attempt to "alert" higher brain regions that something potentially significant has occurred. In schizophrenia, the size of the electrical response is substantially reduced. This reduction in turn correlates highly with reduced overall function as rated by clinicians, suggesting a critical role of MMN in normal brain function.

More recent studies at NKI have investigated further consequences of this basic deficit in ability to detect sound patterns. During speech, modulation of intonation (termed "prosody") is used to carry a wide range of information: for example, whether a series of words is a statement or a question, or whether the speaker is happy or sad. As with MMN, individuals with schizophrenia have difficulty in detecting the prosody of speech and thus determining emotion based upon tone of voice. The deficit is particularly severe

see Research Center on page 34

Sustainability for Systems of Care

By Angie Kays-Burden, LMSW
Project Director
Orange County's System of Care

When Orange County, NY received a "System of Care" grant in October 2008, our community set out on a collaborative and ambitious journey to transform the way we care for youth with serious mental health challenges, and their families. Since 1993, the Substance Abuse and Mental Health Services Administration's Child Mental Health Initiative has funded 144 sites across the country, to improve and enhance services and supports for youth with social, emotional and behavioral challenges. Eighteen new communities received grants in 2008, including Chataqua, Nassau and Orange counties in New York State. A new round of 20 funded communities were announced in October 2009, and included Onondaga County, Syracuse, New York. The six-year, nine million dollar initiative requires

equal partnership between families, youth, and child-serving agencies (e.g. social services, courts, probation, mental health and schools), and shared, community decisionmaking instead of a traditional "top-down" approach. Grantees must work to ensure that their Systems of Care are family-driven, youth-guided, community-based, culturally-competent, and sustained beyond the life of the grant.

The focus on "sustainability" separates System of Care from other grant programs, and, given our current economy, makes the initiative even more challenging. A federally-funded System of Care is not considered a success unless the positive changes that are made during the six year term continue after the grant dollars end. The funding serves as "venture capital" to enable communities to make long-term improvements that will lead to a more responsive and effective System of Care at the end of federal involvement. Because an intensive evaluation is involved, communities learn which services and supports are making a difference in the lives of youth and families, and can

direct resources accordingly. As agencies develop better ways of working together to provide effective care, cost-savings that result are re-invested back into the enhanced system, and provide a means to sustain the changes. A community's prospects to develop a successful System of Care increase greatly when the initiative is implemented not as a "mental health project", but as a collaborative effort of many agencies that embrace community transformation, and that share ownership, decision-making, and resources towards that end.

State-wide policies and partnerships also play a role in sustainability. There are nine funded System of Care communities in New York State alone, including current grantees, and those that have finished their grant terms. Many New York communities are not currently funded by SAMHSA, but have equally significant systems of care. It is important to realize that funded System of Care communities are not sustaining a "grant program", but endeavoring to make permanent the improvements that result in better outcomes

for youth, and their families. Both funded and non-funded communities will benefit from overcoming the obstacles to sustainability that exist at both the local and state level. It is therefore critical that communities without federal grants are recognized for their systems of care, and join with federally-funded communities to work together on relevant issues.

Many System of Care goals align directly with "The Children's Plan of New York State" (<http://www.omh.state.ny.us/omhweb/engage/>), submitted in October 2008 to Governor Paterson and the Majority leaders of the Senate and the House. Signed by nine commissioners of separate child-serving state agencies, this thoughtful, forward-thinking plan recognizes that the well-being of our children is everyone's responsibility. The plan seeks to reduce fragmentation between state agencies, ensure effective and integrated services and develop a culturally-competent workforce "steeped in a new paradigm of integrated, family-driven care."

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MENTAL HEALTH NEWSDESK

Research Project to Test Approaches to Altering the Course of Schizophrenia *Recovery Act Funds Will Support First Phase of Project*

By The National Institute
of Mental Health (NIMH)

The National Institute of Mental Health (NIMH) is launching a large-scale research project to explore whether using early and aggressive treatment, individually targeted and integrating a variety of different therapeutic approaches, will reduce the symptoms and prevent the gradual deterioration of functioning that is characteristic of chronic schizophrenia.

The Recovery After an Initial Schizophrenia Episode (RAISE) project is being funded by NIMH with additional support from the American Recovery and Reinvestment Act (ARRA). RAISE is a model example of how money from the Recovery Act can accelerate science related to public health problems and potentially benefit those citizens most in need.

"This new initiative will help us determine whether intervention that is started early, incorporates diverse treatment and rehabilitation approaches, and is sustained over time, can make it possible for more people with schizophrenia to return successfully to work and school," said NIMH Director Thomas R. Insel, M.D. "Moreover, the interventions being tested will be designed from the outset to be readily adopted in real-world health care settings and quickly put into practice."



Despite the availability of moderately effective treatments, such as antipsychotic medications and various psychosocial interventions, people with schizophrenia often do not receive treatment until the disease is already well-established, with recurrent episodes of psychosis, resulting in costly multiple hospitalizations and disabilities that can last for decades. Periods of unemployment, homelessness, and incarceration are common, making schizophrenia a costly disease for individuals,

their families, and the community at large.

RAISE will test approaches that involve intervening immediately upon first diagnosis, systematically incorporating the range of options that are now available in a more piecemeal fashion to people with schizophrenia. These options include medications, psychosocial treatments, and rehabilitation, including teaching patients and families how to manage the disease. The hope is that such a coordinated approach tailored to each individual and

sustained over time may make lasting differences in the acceptability of treatment and overall function.

Agencies and organizations that play a role in providing health care and other services to people with schizophrenia will have an opportunity to participate in the design of the interventions to be evaluated by RAISE. Federal organizations, including the Substance Abuse and Mental Health Services Administration, the Social Security Administration, the Centers for Medicare and Medicaid Services, the Department of Veterans Affairs, the Walter Reed Army Medical Center, and the National Institute on Drug Abuse, will be involved along with mental health care consumers and family members, private health care providers, additional scientific experts, and state and local agencies. Other agencies may become involved as the project proceeds. Involving these stakeholders will help ensure that, if successful, this evidence-based approach can be disseminated and adopted rapidly, thus significantly speeding the transition between research findings and their use in real-world practice.

Two research groups will work in parallel to develop and test potential intervention approaches. One group will be led by John M. Kane, M.D., of the Zucker Hillside Hospital, Feinstein Institute for

see Research Project on page 20

Schizophrenia Linked to Over-expression of Gene in Fetal Brain *Excess of Shortened Forms Could Lead to Abnormal Brain Development*

By The National Institute
of Mental Health (NIMH)

A gene called DISC1, (for "disrupted in schizophrenia") has been a leading contender among possible genetic causes since it was implicated in schizophrenia in a large Scottish clan two decades ago. The DISC1 gene codes for a protein important for brain development, as well as for mood and memory - functions that are disturbed in schizophrenia. However, until now there have been few clues as to how DISC1 might increase risk for the chronic mental disorder.

A new study suggests how impaired expression of DISC1 might wreak havoc during early critical periods as the developing brain gets wired up. NIMH researchers have discovered that previously unknown shortened forms of the gene were expressed 2.5 times more in the fetal brain than after birth. By contrast, other forms were expressed more evenly across

development. The shortened forms were also over-expressed in brains of adults who had schizophrenia.

"These shortened forms may result in a functionally aberrant and truncated protein that is more highly expressed in the brains of people with schizophrenia" explained NIMH's Dr. Joel Kleinman, who led the research.

Drs. Kleinman, Barbara Lipska, Kenji Nakata, Daniel Weinberger and colleagues, report on their discoveries in postmortem brain tissue online, during the week of August 24, 2009 in the Proceedings of the National Academy of Science (PNAS).

Background: The new findings may help explain the molecular roots of the illness in the Scottish clan, in which more than half of the members developed schizophrenia or other serious mental disorders. Previous studies had traced their disease, in part, to a different aberration, a mismatch called a translocation, in which a chunk of genetic material from one chromosome gets attached to another

chromosome. But this has never been seen in other families. A translocation, like the shorter messenger RNA forms, would result in shortened forms of DISC1 protein. So other affected families and the Scottish clan could in fact share a similar illness process, say the researchers.

Results of This Study: The researchers linked several illness-implicated variations in the DISC1 gene to the shorter forms of DISC1 products, called messenger RNAs, that transform the gene into protein. The results suggest that variations in the DISC1 gene boost risk for schizophrenia by producing shortened messenger RNAs that are predominantly expressed during the formative period when the fetal brain is taking shape.

Significance: "Our results cast a new light on apparent failures to replicate findings that have long plagued psychiatric genetics" said Kleinman. "We discovered that different genetic variations can result in the same or similar messenger RNAs and protein. That means that different studies could turn up different variations

and still be pointing to the same underlying disease process. So some findings thought to be non-replications may ultimately prove to be replications."

Since at least a half-dozen genes implicated in schizophrenia by the NIMH group interact with DISC1, the downstream adverse effects of impaired DISC1 on brain systems are likely considerable, said Kleinman.

What's Next: One of the suspect gene variants associated with a shortened messenger RNAs is detectable in white blood cells, raising the possibility that it could someday be used as a genetic marker for the illness.

NIMH's Dr. Joel Kleinman explained how the DISC1 gene may increase risk for schizophrenia at a recent NIMH seminar.

Reference: Nakata K, Lipska BL, Hyde TM, Ye T, Fink E, Morita Y, Vakkalanka R, Bareboim M, Sei Y, Weinberger DR, Kleinman JE. DISC1 splice variants are unregulated in schizophrenia and associated with risk polymorphisms. Aug 24, 2009 PNAS.

One Agency's (and the System's) Pathway to *Recovery*

By Peter Beitchman, DSW
Executive Director
The Bridge

Here's a prescription for how to approach treatment of people with schizophrenia: "mental illness can be alleviated if the person is treated in a considerate manner, if he has the opportunity to talk about his trouble, if his interest is stimulated and if he is kept actively involved in life." What may surprise you is that this prescription was written in 1806 by Phillipe Pinel, the founder of the *moral treatment* movement in France. What Pinel prescribed, before the advent of Freudian psychology, our modern understanding of the biological underpinnings of serious mental illness, and today's focus on active recovery, was revolutionary at a time when mental illness was thought to be a matter of religious possession. In defining mental illness as a *medical* condition and prescribing consideration, supportive verbal therapy, and active engagement in life, Pinel, and his followers laid the foundation for the evolution of mental health policy in America.

Pinel conceptualized the *asylum* as the place where his *moral treatment* would be carried out, where "patients" (a revolutionary concept in contrast to the "possessed") would live and work in a therapeutic environment. In the 1840s and 50s, the crusaders in the United States (notably Dorothea Dix) successfully advocated state-by-state for the establishment of *asylums* that evolved into the State hospitals that dominated the system for 100 years. Sadly, the vision of *moral treatment* was short-lived in the United States where the state hospitals evolved into the custodial, largely non-therapeutic institutions of the 20th century.

By the 1950s, the New York State psychiatric hospital system had an astonishing 93,000 patients. The cost of the system and the patient-care scandals that regularly rocked and embarrassed professionals and legislators alike, combined with the nascent community mental health movement that envisioned ending the institutional isolation of the mentally ill in favor of community-based care, set the stage for reforms to come. 1954 was the year that New York enacted historic community mental health legislation and Thorazine was introduced as the first effective anti-psychotic medication.

It was also the year that The Bridge, the community-based mental health agency in New York City that provides services to more than 1,600 men and women with serious mental health conditions, was founded. The history of The Bridge reflects the evolution and revolutions that have occurred in the mental health system over the past 55 years. It's an instructive history, charting the system's path to *recovery*.

Given the undeveloped state of community mental health in 1954 it is not surprising that it was a group of patients who had been together in a psychiatric hospital and who were discharged with medication prescriptions in-hand and appointment slips for follow-up clinic visits, who joined together to form their own support program, giving birth to The Bridge.



Peter Beitchman, DSW

For the next 15 years The Bridge was a kind off self-help psychosocial club. The "members" (a term still used by many today), supported by a group of volunteers who raised money to lease space and provide other necessities, participated together in social and mutual-aid activities. The primary value of the group was *non-institutionalism*, staying out of the hospital. The agency served as a place of friendship, there was no professional staff and the role of the members was to socialize and provide mutual support.

By 1969 the policy of deinstitutionalization was in full swing. Thousands of patients were discharged from the five State psychiatric hospitals that served New York City. The Upper Westside of Manhattan, with its abundance of inexpensive single-room occupancy hotels, was a magnet for those discharged and, with few program options, both the quality of life of those discharged and the neighborhood were seriously impacted. It was then that The Bridge, located on the Upper Westside, was sought out by the State Office of Mental Health and offered its first government contract that combined State, City and agency matching funds.

The first order of business was to hire the agency's first professional Executive Director who was a social worker, psychoanalyst and group psychotherapist. The first thing he brought to the task was the theory of the origin of schizophrenia that was widely accepted at the time: the schizophrenogenic family. According to this theory, the cause of schizophrenia could be traced directly to deviant and harmful family interactions. His response to this theoretical proposition was to create in The Bridge "a second chance family" in which the new family, comprised of staff, would offer a corrective family relationship based on caring and nurturing. When combined with the second major idea he brought from social work, the importance of addressing basic living needs such as food, clothing, safety, income and medical benefits, decent housing, and daily structure, the agency quickly

became focused around a paternalistic paradigm in which the staff assumed the role of parents with the clients viewed as children to be taken care of indefinitely.

This paradigm flowered in the 1970s and well into the 80s, as the agency added a number of programs, at the heart of which was a 12-hour-a-day Continuing Day treatment Program that operated 365 day-a-year. In 1979, in response to the poor living conditions that many clients endured, the agency offered its first housing programs.

In the late 1980s a crucial change process began, and significantly it was initiated by the agency's clients. In a confirmation of Abraham Maslow's concept of the *hierarchy of human needs*, the clients acknowledged that they were indeed being well cared for – with 365 days of program, quality housing, their entitlements in place and medication therapy all under one roof. The clients then asked what the agency had to address their growing desire to do more? When asked what they wanted, their response was: *work*. Following the clients' lead, in the late 80s The Bridge started offering vocational services (job training and experience, placement in competitive employment) funded by both the State Office of Mental Health and, later, by what is today's City Department of Health and Mental Hygiene.

It was the advent of vocational ser-

vices and the goal directed clients who eagerly participated in them that began the agency shift to rehabilitation. In addition, advances in the science of understanding schizophrenia had a major impact on the agency. With the schizophrenogenic family theory repudiated and discarded and with new understanding of the biological underpinnings of the disorder, "the second chance family" paradigm was challenged. The client role was shifting from passive recipient of services to active pursuer of individual life goals; the agency function was shifting from nurturing to rehabilitation.

The new paradigm certainly challenged staff whose role was being redefined from parent to facilitator/teacher. This shift not only required acquiring the new technologies of rehabilitation, but also entailed embracing a new set of values, which agency leadership promoted but which were met with understandable resistance. In this new paradigm, which required individualized services, staff's role was to encourage clients to define their *own* goals, a revolutionary idea.

In 1998 the seminal PORT Study (*Schizophrenia Bulletin* 24(1):1-10, 1998 NIMH) was published with its 30 consensus recommendations of practices that improve outcome for persons with

see Pathway to Recovery on page 30



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The Future of Mental Health Care: Better Services and More Research

By Jeffrey A. Lieberman, MD
Chairman of Psychiatry, Columbia
University College of Physicians and
Surgeons, Director, New York State
Psychiatric Institute

For someone who suffers from a mental illness, the chances for receiving effective treatment and recovering are better now than ever in human history. Incredible as this may sound, it is true. We currently can do more for patients with serious mental illnesses like schizophrenia, schizoaffective disorder and major mood disorders using a range of pharmacologic agents and psychosocial treatments than could any of our predecessors. Moreover, it seems clear to anyone who is in a position to know that the best is yet to come.

At the same time, it is clear to mental health care providers and consumers alike that our treatments have significant limitations, as the CATIE project and other studies have shown, and the delivery of mental health care can be improved. There are two strategies to advance the quality of mental health care that we can pursue. The first is doing more and better with our current knowledge and treatments for mental illness. The second is by pursuing scientific research and making use of future progress and breakthroughs.

Currently, we employ a range of pharmacologic agents and psychosocial therapies and services for the clinical care of patients with serious mental illnesses. However, as providers we do not or cannot avail ourselves of these treatments systematically or uniformly. Many of our medication practices are at variance with existing evidence and clinical logic. Most of our patients receive multiple medications in numerous combinations; a practice of polypharmacy for which there is little empirical basis. They also suffer from elevated rates of psychiatric and medical comorbidity, which may be contributed to, in part, by their medications. In addition, clozapine, the antipsychotic drug with proven superior efficacy, is greatly underutilized. Similarly, long acting injectable medications, which could be used to enhance treatment adherence, are only infrequently used.

Psychosocial treatments and services including case management, psychotherapy, cognitive remediation, social skills training, vocational rehabilitation, supported education and employment and assertive community treatment are not widely available, adequately reimbursed or uniformly applied.

Thus, it would seem that by utilizing currently available treatments and services more effectively we could realize substantial benefits for mental health care. However, we cannot overlook the fact that there are numerous and complicated systemic challenges to aligning treatments with evidence and configuring comprehensive services, not to mention the enormous difficulty of providing for their financing. In New York State we are fortunate to have outstanding leadership by the Office of Mental Health with initiatives underway to promote evidence based services, prescribing practices and the use of



Jeffrey A. Lieberman, MD

electronic medical records. Consequently, clinicians and providers in New York State are positioned to lead the way in the effort to enhance the quality of mental health care and enable better outcomes for our patients.

Even with the optimal use of currently available knowledge, there will still be enormous unmet needs in the care of people who suffer with serious mental illnesses. We still do not know the causes of mental illness and have no diagnostic tests for them. Many patients are only partially responsive and some wholly unresponsive to existing treatments, and we lack treatments for many disorders (Alzheimer's disease, autism) or aspects of disorders (e.g. negative symptoms and cognitive impairment in schizophrenia). And we certainly have nothing that approaches a cure for any mental illness.

Progress in these areas will require intensive scientific research. In this regard we are fortunate that the biomedical research enterprise that will inform psychiatric medicine and mental health care is burgeoning and gaining momentum. Brain disorders that express themselves through disturbances in mental functions and behavior are no longer being ignored by mainstream medical research. Of the broad array of research areas that bear on the understanding and treatment of mental illness, I would like to comment on two that are likely to transform the practice of psychiatric medicine and the way in which we provide mental health care in the immediate future.

The first is early detection and intervention research. In recent years, several lines of investigation have demonstrated the benefits of decreasing the duration of untreated illness and providing effective treatment early in the course of psychotic disorders like schizophrenia. This work has led to a passionate movement to develop early psychosis treatment programs around the world. The goal is to identify patients who are at risk for psychotic disorders or are experiencing early signs and symptoms of psychosis and to treat them before the full syndrome or the disabling effects of the

illness develop. If implemented properly, early detection and intervention can limit the morbidity of psychotic disorders, prevent disability and foster recovery. This could save untold suffering and funds spent on services and disability.

However, there are two main problems that must be overcome to enable the early detection/intervention strategy to be successfully implemented. One is the lack of precise and reliable diagnostic criteria. The current approach identifies persons at "ultra-high risk" for a psychotic disorder using a combination of behavioral criteria along with family history. Even the best of these methodologies produces an unacceptably high false positive rate meaning that 40% to 70% of patients called high-risk cases will not develop a psychotic disorder in the ensuing three years. This means that people called high risk might be given an unwarranted diagnosis and possible treatment with its potential attendant side effects unnecessarily.

For this reason, it is imperative that we improve the diagnostic precision of our definition of high-risk persons. I believe that this will be done through the use of laboratory tests including genotyping, proteomic analysis, neuroimaging and electrophysiologic assessments. The NIMH has initiated major programs in the area of early detection/intervention. One, called NAPLS (North American Prodrome Longitudinal Study) led by investigators at UCLA is a consortium of academic medical centers that are conducting research on the diagnosis and treatment of persons at high risk for psychotic disorders and in the prodromal phase of illness. The second is the RAISE project (Recovery After an Initial Schizophrenia Episode) the goal of which is to develop and test an optimal intervention program for patients with first episode psychosis that will limit disability and foster recovery. The lead sites for this ambitious project are in New York at Columbia University's New York State Psychiatric Institute and the Zucker Hillside Hospital.

The other problem that must be addressed before the early detection/intervention strategy can be employed effectively is to determine the optimal therapeutic interventions. We do not know if antipsychotic drugs, which are used for the acute and chronic stages of the illness, should be used in the premorbid and prodromal stages as well. We do not know if the optimal interventions are pharmacologic or psychosocial. Therefore, better diagnostic methods and studies of therapeutic interventions are needed before this potentially transformative strategy will be ready for application in mental health care.

The second research area that will rapidly yield important benefits involves the practice of polypharmacy. Currently, polypharmacy is pervasive in mental health care with the vast majority of patients receiving multiple psychotropic medications. However, this practice, widespread as it may be, has little scientific basis and seems mainly born from efforts by clinicians to enhance the therapeutic response of patients by adding more drugs and trying new combinations. This is in large part due to the lack of pro-

gress in developing new drugs with novel mechanisms of action. In fact the medications used for the psychotic and mood disorders are mechanistically pretty much the same as the prototypes that were developed over 50 years ago. However, several things have occurred in recent years that I believe will set the stage for the development of new drugs and new approaches to what can be called a scientifically based or rational polypharmacy.

The first development is that researchers and pharmaceutical companies have realized that there may not be a "magic bullet" for disorders like schizophrenia and bipolar disorder, which have multiple pathologic dimensions. Different pharmacologic actions may be required to remediate the distinct pathophysiologies that underlie the different symptom dimensions of the illness. Schizophrenia provides a good example. For almost a half-century, we have used drugs that block dopamine at the D-2 receptors to treat psychosis while searching for drugs that would also alleviate negative symptoms and cognitive deficits. However, we now know that the antipsychotic drugs whether they are first, second or third generation do not have any significant efficacy against negative and cognitive symptoms. Thus, the focus of drug development has shifted to targeting other systems than dopamine through the development of separate drugs that could be used as adjuncts to antipsychotics.

At the same time the FDA has sanctioned this approach by stating its willingness to approve drugs for indications such as cognitive enhancement and negative symptoms. Consequently, there is now a great deal of research activity underway to develop medications as adjunctive treatments that add to the therapeutic effects of antipsychotics.

The NIMH has helped to facilitate this process by their sponsorship of the TURNS program (Treatment Units for Research on Neurocognition in Schizophrenia). The purpose of this program comprised by eight academic medical centers and led by UCLA is to glean from the pharmaceutical industry promising novel compounds for cognitive enhancement and rigorously test them in phase II "proof of concept" studies. This program has been very successful and will be reporting out its results over the next year.

Ultimately, clinicians will be able to utilize multiple medications from different classes with different mechanisms of action to treat the various aspects of mental illnesses like schizophrenia and mood disorders in a way that is similar to what is done in managing cardiovascular disease.

Before concluding I would also like to comment on the ascendance of comparative effectiveness research as a priority in health care and for the U.S. government. For too long there has been no reliable source of information for clinicians to know how marketed treatments compared to each other and which are most effective and in which patients. Most clinical trials and comparisons of drugs are sponsored by the pharmaceutical industry, first to see they work at all in a given disease condition

see The Future on page 38

Understanding and Treating Schizophrenia

A Comprehensive Review from the National Institute of Mental Health

By The National Institute of Mental Health (NIMH)

Schizophrenia is a chronic, severe, and disabling brain disorder that has affected people throughout history. About 1 percent of Americans have this illness.

People with the disorder may hear voices other people don't hear. They may believe other people are reading their minds, controlling their thoughts, or plotting to harm them. This can terrify people with the illness and make them withdrawn or extremely agitated.

People with schizophrenia may not make sense when they talk. They may sit for hours without moving or talking. Sometimes people with schizophrenia seem perfectly fine until they talk about what they are really thinking.

Families and society are affected by schizophrenia too. Many people with schizophrenia have difficulty holding a job or caring for themselves, so they rely on others for help.

Treatment helps relieve many symptoms of schizophrenia, but most people who have the disorder cope with symptoms throughout their lives. However, many people with schizophrenia can lead rewarding and meaningful lives in their communities. Researchers are developing more effective medications and using new research tools to understand the causes of schizophrenia. In the years to come, this work may help prevent and better treat the illness.

What are the Symptoms of Schizophrenia?

The symptoms of schizophrenia fall into three broad categories: positive symptoms, negative symptoms, and cognitive symptoms.

Positive symptoms

Positive symptoms are psychotic behaviors not seen in healthy people. People with positive symptoms often "lose touch" with reality. These symptoms can come and go. Sometimes they are severe and at other times hardly noticeable, de-



pending on whether the individual is receiving treatment. They include the following:

Hallucinations are things a person sees, hears, smells, or feels that no one else can see, hear, smell, or feel. "Voices" are the most common type of hallucination in schizophrenia. Many people with the disorder hear voices. The voices may talk to the person about his or her behavior, order the person to do things, or warn the person of danger. Sometimes the voices talk to each other. People with schizophrenia may hear voices for a long time before family and friends notice the problem.

Other types of hallucinations include seeing people or objects that are not there, smelling odors that no one else detects, and feeling things like invisible fingers touching their bodies when no one is near.

Delusions are false beliefs that are not part of the person's culture and do not change. The person believes delusions even after other people prove that the beliefs are not true or logical. People with schizophrenia can have delusions that seem bizarre, such as believing that neighbors can control their behavior with magnetic waves. They may also believe that people on television are directing special messages to them, or that radio stations are broadcasting their thoughts

aloud to others. Sometimes they believe they are someone else, such as a famous historical figure. They may have paranoid delusions and believe that others are trying to harm them, such as by cheating, harassing, poisoning, spying on, or plotting against them or the people they care about. These beliefs are called "delusions of persecution."

Thought disorders are unusual or dysfunctional ways of thinking. One form of thought disorder is called "disorganized thinking." This is when a person has trouble organizing his or her thoughts or connecting them logically. They may talk in a garbled way that is hard to understand. Another form is called "thought blocking." This is when a person stops speaking abruptly in the middle of a thought. When asked why he or she stopped talking, the person may say that it felt as if the thought had been taken out of his or her head. Finally, a person with a thought disorder might make up meaningless words, or "neologisms."

Movement disorders may appear as agitated body movements. A person with a movement disorder may repeat certain motions over and over. In the other extreme, a person may become catatonic. Catatonia is a state in which a person does not move and does not respond to others. Catatonia is rare today, but it was more

common when treatment for schizophrenia was not available.

Negative symptoms

Negative symptoms are associated with disruptions to normal emotions and behaviors. These symptoms are harder to recognize as part of the disorder and can be mistaken for depression or other conditions. These symptoms include the following:

- "Flat affect" (a person's face does not move or he or she talks in a dull or monotonous voice)
- Lack of pleasure in everyday life
- Lack of ability to begin and sustain planned activities
- Speaking little, even when forced to interact.

People with negative symptoms need help with everyday tasks. They often neglect basic personal hygiene. This may make them seem lazy or unwilling to help themselves, but the problems are symptoms caused by the schizophrenia.

Cognitive symptoms

Cognitive symptoms are subtle. Like negative symptoms, cognitive symptoms may be difficult to recognize as part of the disorder. Often, they are detected only when other tests are performed. Cognitive symptoms include the following:

- Poor "executive functioning" (the ability to understand information and use it to make decisions)
- Trouble focusing or paying attention
- Problems with "working memory" (the ability to use information immediately after learning it).

Cognitive symptoms often make it hard to lead a normal life and earn a living. They can cause great emotional distress.

see Comprehensive Review on page 35



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— Point of View —

Schizophrenia, The Mortality Gap, and Suicide

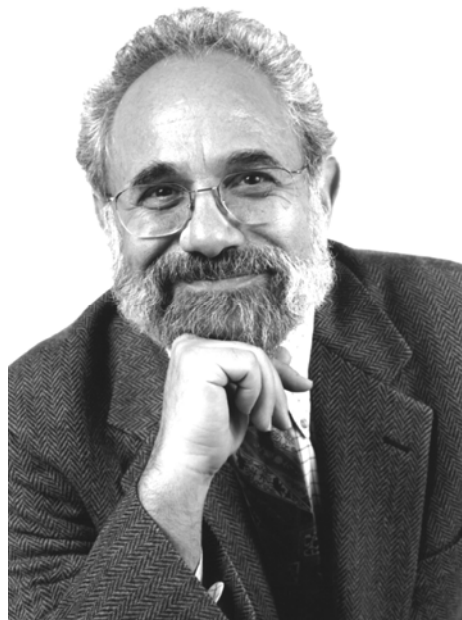
By Michael B. Friedman, LMSW

People with serious mental illness have a much lower life expectancy than the general population; estimates range from 9 to 32 years. Recent recognition of this mortality gap has led to increasing efforts to improve the health of these people by improving their access to health care and by providing health promotion activities such as smoking cessation, better diet, and more exercise.

These efforts are extremely important and long overdue. However, by themselves they will not address the mortality gap fully because 30-40% of the mortality gap is due to deaths from non-natural causes—homicide, suicide, and accidents—with suicide being by far the most common. In fact, suicide is the leading cause of death of younger people with schizophrenia. And people with schizophrenia are 12 times more likely to take their own lives than the general population.

Addressing the mortality gap should, therefore, involve an effort to reduce suicides by people with schizophrenia. How? By mounting responses to the known risk factors. Here's a somewhat abbreviated list of what researchers have identified.

- Most people with schizophrenia who complete suicide do so early in the course of their illness.
- Their suicide attempts tend to be lethal. I.e., they make comparatively few unsuccessful attempts.
- Suicide risk is highest for people with schizophrenia who also have a deep sense of hopelessness and worthlessness.
- They are particularly vulnerable after the loss of a person about whom they care.



Michael B. Friedman, LMSW

- Thinking about suicide and failed suicide attempts are also significant risk factors.
- Although there is some dispute in the research about whether awareness of one's condition ("insight") is a risk factor, fear of cognitive decline definitely is.
- Surprisingly, hallucinations and delusions—even command hallucinations—do not seem to increase risk of suicide.
- Not surprisingly, the co-occurrence of illegal substance abuse with schizophrenia is a significant risk factor.
- Not surprisingly as well, people who discontinue treatment are also at higher risk of suicide.
- Surprisingly, however, suicide by people with schizophrenia is not correlated with poor physical health.

This list comes from a review of a number of major meta-research studies. Obviously, the findings are useful. But frankly, I find these studies remarkably bloodless. And as I read them, I find myself remembering a man named Al, who was a member of a psychiatric rehabilitation program where I worked in the early 1970s. Al was about 30, tall, strong looking, usually disheveled, and very angry—with a tendency to have frightening verbal outbursts. Despite that, he had a number of friends both in and out of our program. He talked a lot about being thrown out of City College because his brilliance was unappreciated. He knew, he said, the truth about the Universe and talked about it frequently and rapidly in ways that we could not understand. He also spent much of his time writing it all down in notebooks that no one was able to decipher. One other thing—Al was clearly tormented by his loss of promise and hated his life. One day he jumped in front of a subway. Whether it was an impulse or a planned suicide we never knew.

How can we address the problem of suicide among people with schizophrenia, people like Al? Some steps are obvious given the risk factors noted above:

- Early identification and intervention
- Outreach to people who disappear from treatment
- Active efforts to engage them in treatment and rehabilitation where and in ways that they accept
- Serious response to symptoms of depression, especially a sense of hopelessness and worthlessness, suicidal thoughts, or a history of suicide attempts
- Special vigilance after a personal loss
- Integration of treatment of mental and substance use disorders.

This all involves preparing the community at-large to identify suicide risk and giving potential observers—and people in crisis—a number to call (or an internet site that is easy to access) when they need help. It also involves a substantial effort to train mental health, substance abuse, health, and social services providers how to identify suicide risk in people with schizophrenia and how to engage and treat them.

All of this is clearly important. But I keep thinking about Al, and it strikes me that the only thing that would have saved him is a sense of hope.

Fortunately, there is reason to believe that supportive families, contact with other people with schizophrenia who have made satisfying and meaningful lives for themselves, and spiritual faith can help people with schizophrenia get past despair.

Young people with schizophrenia are completing suicide at an alarmingly high rate. That is one of the major reasons why people with serious mental illness die so much younger than the general population. It is very important, therefore, that current efforts to transform mental health policy so as to close the mortality gap address the problem of suicide as well as the problem of poor health.

Michael B. Friedman is the Director of the Center for Policy, Advocacy, and Education of the Mental Health Association of New York City. The opinions expressed in this essay are his own and do not necessarily reflect the views of the Mental Health Association.

Useful Articles

Alexander, MJ., et al. "Coping With Thoughts of Suicide: Techniques Used by Consumers of Mental Health Services", *Psychiatric Services*, September 2009.

see Point of View on page 37

A Sound Bite for Mental Health: The Winner Is...

By Michael B. Friedman, LMSW

In the last issue of *Mental Health News*, I asked for suggestions for a sound bite for mental health—some way of capturing the importance of mental health so effectively that it would lift mental health policy from the lowest circle of the health reform debate to the highest.

Many people responded with very thoughtful suggestions. Conceptually they fall into four categories—(1) link mental health and health, (2) talk about the economic costs of mental illness, (3) use euphemisms, and (4) call for major social change.

Social Change: One person emphasized the civil rights dimension of mental health policy and suggested, "Let people with mental illness out of institutions and into a free life." This is certainly an important message, but I doubt it will influ-

ence the health care reform debate. It could, however, influence the critical need to change policies that support continuing transinstitutionalization.

Euphemisms: Several people observed that the expressions "mental illness" and even "mental health" trigger discomfort and avoidance. Suggested alternatives were "emotional health" instead of "mental health" and "wellness" instead of "health." These, and other, language changes are, I think, good ideas in some circumstances; but it strikes me that "mental health" in its own time was a euphemism that got contaminated by our society's deep discomfort with mental illness. Will other euphemisms have a different fate? One writer shared my reservations and suggested the simple and direct, "Cure mental illness."

Costs: Several people observed that most Americans have no idea how much mental illness costs in direct care and lost productivity. They suggested: "Effective

treatment of mental illness could save over \$300 billion per year", "Poor mental health drives up health costs", and the lengthier but informative "Over an average American life over 50% of us will suffer from a mental illness at a cost of over \$300 billion per year." In addition one person suggested linking the reduction of the costs of untreated mental illness with having enough money to cover the costs of health care reform, an interesting thought but she didn't suggest a sound bite.

These all strike me as useful possibilities, particularly if we emphasized the fact that many, if not most, of the highest cost cases are people with co-occurring serious physical and behavioral health disorders and disabilities. The costs of mental illness are probably far higher than the current estimate of \$300 billion+.

Link Mental Health and Health: By far the most frequent suggestions for a sound bite for mental health link mental

health and health. They include "Mental health is also health", "Good mental health improves overall health", and the very powerful "Good mental health—it's a matter of life and death".

By far the most frequent suggestion as the classic and proverbial, "Sound mind, sound body", including one suggestion to use the Latin, "*Mens sana in corpora sano*". One person suggested a bit more complex formulation, "Sound mind, sound body—but unsound separation is the policy of the day." He also said that he likes the Surgeon General's, "No health without mental health."

These responses all suggest a growing consensus about the need to build an understanding in our society that health and mental health are inextricable.

I am grateful for those who took the time to respond to my request. I'm certainly going to build on some of these suggestions in my future rhetoric. I hope you will too.

The NYSPA Report

Report on the Veterans Mental Health Training Initiative

By Richard Gallo, Government Relations Advocate, NYSPA and Karin Moran, Director of Policy, NASW-NYS

In response to the severe shortage of mental health professionals skilled in combat related mental health issues, the New York State Psychiatric Association (NYSPA), the National Association of Social Workers – New York State Chapter (NASW-NYS) and the Medical Society for the State of New York (MSSNY) have partnered over many months to develop and now conduct the *Veterans Mental Health Training Initiative* (VMHTI) -- a series of education and training institutes focusing on the mental health needs of combat veterans and their families.

As service members return to New York (estimated at seventy-seven thousand), they and their families are often in need of expert mental health care; yet there is a short supply of mental health professionals who are adequately trained in veterans-specific mental health issues. The situation has prompted New York State executive agencies to engage in various collaborative efforts aimed at coordinating veterans' health and mental health care across agency jurisdictions. Likewise, the Veterans Administration has taken extraordinary steps to assure appropriate health and mental health services are available to veterans and their families.

However, despite the attention and resources government has provided to the mental health needs of combat veterans, an ever increasing number of veterans with combat-related mental and substance abuse disorders are seeking care in their communities through emergency rooms, mental health clinics, social services agencies, primary care physicians and clinicians in private practice. It is in these settings where the aforementioned workforce shortages are most acute and thus the VMHTI target audience.

Clearly, the State of New York and the country at large are facing a formidable challenge in serving the mental health needs of veterans returning from active duty in Iraq and Afghanistan. Since the beginning of Operation Enduring Freedom and Operation Iraqi Freedom, over one and a half million active duty and reserve members of the U.S. military have been deployed to Iraq or Afghanistan, and nearly half have been redeployed. With each deployment, our service members encounter extreme strains on their physical and mental health, which, in many cases has resulted in unprecedented rates of health and mental health problems, most notably posttraumatic stress disorder (PTSD) and traumatic brain injury (TBI). Equally alarming, are numerous reports of increased suicide, addiction and homelessness among our returning soldiers. Further, family members are struggling with the ramifications of extended and / or multiple deployments, resulting in serious emotional and psychological tolls.

As evidenced by a number of reports, including the recent landmark study in the *Journal of the American Medical Association*,



Richard Gallo

tion, posttraumatic stress disorder rates are reportedly as high as 24.5 percent for National Guard and Reserve troops serving in Iraq. In addition to high rates of posttraumatic stress disorder, providers in the mental health community have also begun reporting increased cases of traumatic brain injury sustained while in combat in Iraq and Afghanistan due in large part to the use of Improvised Explosive Devices (IED). Equally disturbing is the rate at which TBI has been misdiagnosed as PTSD. Numerous reports have told the story of soldiers returning from Iraq and Afghanistan with brain trauma, but because there are no visible head wounds, symptoms such as memory loss and confusion are often mistaken as indicators of PTSD.

Recent Post Deployment Health Reassessment (PDHRA) data show that up to 38 percent of soldiers and 31 percent of Marines are suffering from negative psychological symptoms. In addition, the Department of Defense Task Force on Veterans' Mental Health recently reported elevated rates of major depression and substance abuse. Untreated psychological symptoms all too often result in self medication, leading to unprecedented spikes in substance abuse rates among soldiers. According to the American Forces Press Service, 21 percent of service members admit to drinking heavily; significantly higher than in the civilian sector. Reports of drug abuse among returning service members have also increased since the beginning of the Afghanistan and Iraq wars. Moreover, a recent Harvard study on the long term costs of the Iraq war stated that the current VA waiting lists for substance abuse treatment "render care virtually inaccessible." As such, it is vitally important that community mental health providers recognize and screen for symptoms of self-medication among our returning soldiers.

Given this increased need for community mental health services, it is critical that we heed the findings of recent reports by the Department of Defense, and the



Karin Moran

President's Commission on Care for America's Wounded Warriors, which cited an overwhelming need to train mental health providers in mental illnesses with unique etiological roots to combat situations. In addition, providers need to be well-versed in the distinct context of mental health within the military culture. As Dr. Edward Tick, Executive Director of Soldier's Heart, a New York State based agency serving veterans, stated in

recent testimony, war-related trauma has particular characteristics for which practitioners must have expert and specific training. In that same hearing, Dr. Yuval Neria of the New York State Psychiatric Institute also noted the restricted access veterans and their family members face when seeking mental health care in New York and beyond, suggesting that mental health consumers require training in accessing systems of care.

The first VMHTI Institute, entitled "Symposium on Enhancing Community Capacity to Meet the Needs of Returning Service Members and their Families," was held on Thursday, September 17, 2009, at Hofstra University on Long Island. The day-long program included presentations and workshops for providers on assessing and treating combat-related mental health disorders, such as post-traumatic stress disorder, traumatic brain injury and substance abuse disorders, as well as family issues related to deployment and re-entry. VMHTI Institutes are offered free of charge and are open to mental health professionals, members of the military, veterans and their families.

Future Institutes will be held on the following dates: November 19, 2009 Rochester at the Radisson Hotel Rochester Riverside; April 23, 2010 in NYC at Fordham University; May 21, 2010 in the Hudson Valley at SUNY New Paltz.

The VMHTI brochure and institute registration information can be accessed at: <http://www.naswnys.org/tiglance.htm>.



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The Economics of Recovery: Finding Your Voice

By Donald M. Fitch, MS
Executive Director
Center for Career Freedom

It had been a long day; half-a-dozen intake interviews with several Government benefit applications for SSA disability with the usual back-up documentation. I was drowning in paper.

I've probably completed fifteen hundred applications for Government benefits in the past ten years. At this rate, with an estimated SPMI population of twenty thousand in the county (2%), I was looking at one-hundred more years of paperwork! I got into counseling to help people, not fill out forms. There had to be a better way. There was no money for new hires or benefits training & I couldn't clone myself, so what was I to do?

The solution was sitting right on my desk; my PC is connected to the internet which can reach millions of people, 24/7, for free. If I could create the right content and post it on the right site for our population, their friends, families, therapists, counselors, physicians, etc. to see at their convenience and, on our own computers for our staff & students, it might relieve some of the pressure.

I had read that eighty percent of the U.S. population was now connected to the internet, twenty-nine percent watched videos, twenty-five percent read blogs (newsletters) and the same number visited social networking sites like Facebook and My Space. But I wasn't searching for old classmates, or a new spouse – I just wanted folks-in-need to know where they could get some street smarts help in securing critical Government benefits and to learn about our NYSED/Microsoft Office Certified Training in the process.



Donald M. Fitch, MS

After a few minutes surfing, I found many non-profits had posted their agencies' profiles to raise awareness of their mission, publicize events, recruit volunteers & solicit donations. They didn't have to get personal to help people. And, these sites provided a template for us to develop our own site.

For our first venture, we chose to produce a YouTube video to demonstrate how to complete SSA's disability application and to prepare for the interview. With the help of a NYU Film School student, we filmed a five minute dramatization including how Social Security defines "disability", what questions they ask, what terms are used to describe the disability and what documentation is required.

After the video, we invited the viewer to download our Application Packet consisting of SSA's 3368 application form, the Cen-

ter's Guide to Disability Evaluation, Document Checklist, and Guide to Government Benefits. We have had over eight-hundred downloads in the past two months. To view it, go to: www.economicsofrecovery.org and click on: YouTube Video.

YouTube.com: There are over ninety-thousand "non-profit" videos posted on YouTube and over thirty-thousand videos for "Mental Health".

Facebook.com: Modeled on the student yearbook photo/profile format, Facebook was created to help Harvard students get to know one another. Personal profiles morphed into networks based on like studies, interests, hometowns, workplaces, etc. Users can join up to two hundred groups, find people, keep up with friends, play games, and even join a Virtual Pet Society. The most popular uses of Facebook are personal profile updates, jobs, relationship status, photos/videos, event planning, etc. You can also send virtual gifts and post classified ads.

Facebook is currently the most popular social networking site in the world with over one-hundred thirty million unique visitors each month. Some fourteen million photos are uploaded to Facebook, daily. Among college students, Facebook is rated as important as their iPod and beer.

It has been banned at times by China, Syria, Iran and Morocco for promoting attacks on authorities and organizing opposition movements.

There are some thirty-thousand Non-profits on Facebook visited by two-thousand "fans." Over sixteen thousand Mental Health Blogs (Newsletters) are posted including New York-Presbyterian's Informational Directory. Dozens of ads for NYC Psychiatrists and Therapists appear above and below their listing.

Myspace.com: A competitor of Face-

Book, the My Space personal profile includes the usual sections on interests, status, zodiac signs, photos, a bulletin board for messages, music, videos, groups, news, classifieds, karaoke, TV, etc. My Space attracts some one hundred seventeen million unique visitors each month.

A "Mental Health" search turned up over fifty-thousand entries including several NAMI chapters and New York-Presbyterian Hospital's Directory. However, we found less than one-hundred Non-profit profiles contained in MySpace's Impact Directory.

Twitter.com: At six million viewers per month, Twitter is the newest and fastest growing social website and is ranked the third most popular website in the world.

Of all the ways to communicate, Twitter's purpose is perhaps the simplest; it's designed to answer the question; "what are you doing?" Unlike the other social networking sites, there are no pictures, no videos or sounds (yet), just text. But, no more than 140 characters of text.

The word "twitter" is defined as "a short burst of inconsequential information." "Pointless babble" makes up about half of the messages or "tweets," and the rest are considered to have "pass along value" which ranges from tweets about Miley Cyrus' one million fans who wait for her to explain why she quit Twittering, to where to buy UGGs on sale, to Iranian protests, California brushfires, downed aircraft, and NASA Space Stations. A U.S. Army Intelligence report characterized Twitter as a "potential terrorist tool".

With the potential of hundreds of millions of people becoming aware of your agency's services 24/7 for pennies, the social networking sites offer a unique opportunity to expand your reach and to fulfill your mission.



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Sustainability from page 6

The Children's Plan mirrors local System of Care efforts, provides a unified vision and identifies focus areas for the next five to ten years. Funded and non-funded New York communities would do well to em-

brace The Children's Plan as an excellent starting place for their local System of Care sustainability efforts and advocacy.

Sustaining a quality System of Care requires hard work, flexible thinking and a willingness to set aside individual agendas. While local systems of care may be

good, families and youth tell us that there are still things we can do better. Orange County has embraced the challenge of community transformation at a time when the economy makes it all the more difficult, but important to succeed. Despite the fiscal realities, we are optimistic that

the commitment and partnerships, within and between communities, and at the state and federal level, will be sufficient for the task ahead. Our success is critical.

Angie Kays-Burden works at the Orange County Department of Mental Health in Goshen, New York.

THE MENTAL HEALTH LAWYER



Subjects or Savors: The Rules and Regulations Surrounding Human Clinical Trials of Experimental Psychiatric Medication

By Carolyn R. Wolf, Douglas K. Stern, and Eric Broutman, Esqs.
Abrams, Fensterman, Fensterman, Eisman, Greenberg, Formato & Einiger, LLP

In opening his opinion striking down the Office of Mental Health's regulations controlling the administration of experimental psychiatric medications to patients who lack the capacity to make decisions for themselves, Justice Edward J. Greenfield of the New York Supreme Court poignantly stated:

"The mere mention of experimental medical research on incapacitated human beings—the mentally ill, the profoundly retarded, and minor children summons up visceral reactions with recollections of the brutal Nazi experimentation with helpless subjects in concentration camps, and elicits shudders of revulsion when parallels are suggested"

Strong and powerful words, no doubt, yet, Judge Greenfield goes on to recognize the clear benefits that can be, and have been, obtained with the use of clinical trials on human subjects. And this is the dilemma we are left with. How do we devise protocols that will respect the dignity of the individual while at the same time allow for needed clinical trials on human subjects so that we may further medical science and alleviate the suffering of countless individuals in the future with the lessons these trials teach us?

This article will discuss how New York has attempted to meet these dual and at times juxtaposing goals. Initially, to gain a better understanding of how pharmaceutical drugs get to a stage of human trials this article will discuss the Food and Drug Administration (FDA) process by why drugs are tested, through three clinical stages, on human subjects and ultimately approved or rejected. Lastly, this article will discuss difficulties and potential points of conflict in the FDA process.

The FDA Approval Process

It is the responsibility of the FDA, and specifically, the Center for Drug Evaluation and Research (CDER) within the FDA, to approve new pharmaceutical drugs before they are allowed to be marketed to the public. The process is time consuming and expensive. On average, a new drug requires 8 years of testing and \$350 million dollars in investment before it reaches a local pharmacist. Only one in 1000 compounds that begin laboratory testing will ever make it to the human testing stage.

Initially, before human trials are even contemplated, a pharmaceutical company wishing to market a new drug must synthesize and purify the drug in order to



Carolyn R. Wolf, Esq

develop a compound that has some hope of efficacy. Some limited animal testing is performed and if the pharmaceutical company wishes to seek the approval of the FDA they must begin the human trial clinical stage of testing.

Phase 1 of clinical testing deals with a limited population of individuals, from 20-80 people. These people are mostly healthy and not afflicted with the condition that the drug is meant to treat. Generally, the purpose of this phase is to study the safety of the drug and determine what adverse side-effects the drug may have on the human body and its processes.

In phase 2 the drug is tested on patients with the specific disease the drug is anticipated to treat. The purpose of this phase is to test the efficacy of the drug. This phase is conducted on a much larger scale, typically involving hundreds of patients.

Phase 3 is meant to test the drug on the broader population in numbers that will allow those conducting the study to extrapolate the results of the clinical trial to the general population. In phase 3 the drug is tested on thousands of patients.

Throughout the clinical trial phase Institutional Review Boards (IRBs) are established as a check on these studies and to protect the welfare of the individuals who are the subjects of the study. The IRBs are usually created from a group of experts and laypersons from a diverse background to ensure that a complete review of the study is conducted from a multidisciplinary standpoint.

Assuming all goes well, at the conclusion of this process the drug manufacturer will submit a New Drug Application to the FDA seeking approval of the product. The FDA will consider the efficacy of the drug, the safety of the drug and the overall risk-benefit analysis in determining if the

drug warrants approval. The FDA will also consider the labeling placed on the drug to determine if it is sufficient to warn not only clinicians of the proper use and potential side effects of the drug, but patients as well.

Even after a drug has been approved, the FDA as well as the pharmaceutical company that designed the drug, is charged with monitoring the safety of the product. Reports of serious adverse effects must be reported to the FDA for consideration on whether to alter the labeling on the drug, or most drastically, pull the drug from the market. The most famous example of this was the popular painkiller medication Vioxx.

Over the years, many have complained about the FDA drug approval process. Many of these complaints have revolved around the time and expense it takes for drugs to reach the approval process. The most pervasive complaints have come since the passage of the 1992 Prescription Drug User Fee Act, which altered the budget of the FDA by charging "user fees" to pharmaceutical firms. It is estimated that from 1993 to 2001 the FDA collected \$825 million in user fees from drug companies. With money on such a staggering scale it is not difficult to see where the appearance of a conflict may arise.

While this alteration has resulted in quicker approval times, decreasing from an average of 27 months in 1993 to just 14 months in 2001, by contrast, it has also resulted in more drugs being pulled from the market after they have been approved by the FDA, to the tune of 5.35% of drugs for 1997-2001 as compared to just 1.56% for 1993-1996. Additionally, a review of FDA expert advisory panels, meant to advise the FDA on the drug approval process, revealed that since 1993 more than half of these members had a direct financial interest in the drug or area of research they were charged with evaluating.

Moreover, many of the clinical trials used to test the safety and efficacy of a proposed drug seeking FDA approval are controlled and paid for by the drug company that owns the drug. Hence, the results of clinical trials that produce unfavorable outcomes are often suppressed. Recently, some authorities have brought pressure to bear upon drug companies to publish the results of all clinical trials, regardless of the outcome. In 2004, the New York State Attorney General brought suit against GlaxoSmithKline alleging that the company had suppressed negative results of four studies of its anti-depressant,

see *Experimental* on page 34

Carolyn Reinach Wolf, Esq and Douglas K. Stern, Esq of

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Providing a Second Chance for People with Schizophrenia

By Adam J. Savitz, MD, PhD, Unit Chief,
and Andrew Bloch, MSW, LCSW,
Program Coordinator, Second Chance
Program, New York Presbyterian
Hospital-Payne Whitney Westchester

Despite advances in psychopharmacology, many individuals with schizophrenia remain too impaired to be discharged from the state hospitals. One response to this problem in New York State was the establishment of a unique partnership among a private hospital, the New York Presbyterian Hospital-Payne Whitney Westchester (NYPH-PWW), the New York State Office of Mental Health (OMH), and four community residence providers in New York City. The goal of this partnership was to develop an alternative treatment model for those “untreatable” patients who had been in state hospitals for more than three years, or who had otherwise been unable to establish any substantial tenure in the community.

Such patients would be placed in what was called the “Second Chance Program,” a specialized 30-bed inpatient unit at NYPH-PWW. The program was initially conceived and developed by Rami Kaminski, MD who was the Director of the Family Liaison Bureau at OMH, Ken Terkelsen, MD who was the director of the day treatment program at the time at NYPH-PWW, and Michael Friedman, LMSW who was doing program development at NYPH-PWW. The program opened its doors in the winter of 1998.

Patients are identified by the staff at the state hospitals as potential candidates for Second Chance. All prospective patients are then interviewed for clinical appropriateness, to make sure they understand the nature of the program, that they and their families have had all of their questions answered, and that they are willing to participate voluntarily in the program.

In the Fall of 1999 Steve Silverstein, PhD came to NYPH-PWW from the University of Rochester to become the Program Director of Second Chance. His primary mission at the time was to introduce a comprehensive behavioral treatment program that has long been known to be effective in treating the severe and persistently mentally ill (SPMI) population. Recognizing that behavioral problems as well as symptoms can be major impediments to many patients’ ability to live successfully in the community, behavioral interventions to address behavior excesses (e.g., aggression) and deficits (e.g., social isolation) were implemented at the milieu, group, and individual treatment levels. A point system based on comprehensive observational ratings of both socially inappropriate and appropriate behavior is used for determining on-ward and off-ward privileges. Patients receive daily ratings, and feedback, for appearance and grooming, room cleanliness, behaviors during mealtimes, and preparation for sleep. These specific behaviors were targeted because we knew that the community residences placed a high premium on these skills, as well as that consumers with these skills have longer community tenures than those



Andrew Bloch, MSW, LCSW

without them. The program also uses a token economy, which can be thought of as a prosthetic environment for people with severe cognitive deficits. Patients earn tokens for meeting specific behavioral targets: such targets may be for the behaviors noted above or for aspects of group therapy, including arriving on time, participating and staying for the entire session. These are skills that are important for the patients to have as they re-enter the community and participate in day treatment or prevocational programs. Tokens provide immediate reinforcement for positive, prosocial behaviors and provide a daily sense of success and mastery for even the most impaired individuals. As a patient’s behavior begins to approach community standards the external reinforcers (tokens) are used less, and social and internal controls are relied on more.

Adam Savitz, MD, has been the Unit Chief since July 2001 and has been dedicated to the social learning program as well as to overseeing the psychopharmacology for the patients. The general philosophy is to not over-sedate the patients with medication, for two very important reasons. First, over-sedation simply masks problem behaviors and symptoms which need to be addressed more actively in treatment; and second, the emphasis of Second Chance is to help the patients learn essential skills needed to live in the community, and it is very difficult to learn when over-sedated on medication.

The Second Chance Program model has proven to be quite effective for treating patients who were considered unlikely to be discharged from state hospitals. We have discharged over 350 individuals since the program’s inception and have been able to successfully transition 80% into the community, and 80% of these individuals are out in the community at any given time. Increasingly over the past 1-2 years, we have been working with individuals who would otherwise have been transferred to a state facility for intermediate level of care, and the social learning and token economy has been effective in preventing state hospital transfer for many of



Adam J. Savitz, MD, PhD

these individuals. We have demonstrated that when intensive behavioral treatment is combined with appropriate pharmacology, the number of patients deemed to have treatment refractory psychosis is far lower than when medication alone or medication plus traditional milieu approaches are used.

At the program’s inception, forethought was given to the need for available community residence beds where the patients could be placed once they were ready for re-integration into the community. OMH used reinvestment monies at the time to provide the program with 30 supported housing beds dedicated to Second Chance patients being discharged who needed the support and structure provided by a community residence. This was a vital component of the program as many of our patients have comorbid medical problems such as diabetes and high blood pressure, serious substance abuse histories, as well as histories of involvement with the criminal justice system that make them very difficult to place in the community.

We obtained a commitment from four well-established housing providers in New York City to prioritize the Second Chance Program patients. It was decided at the time to concentrate the 30 beds among fewer housing providers to promote closer and more intensive working relationships between the inpatient setting and housing providers taking the patients, and this proved to be a good decision. We also wanted to use housing providers that were close to where the patients had family and/or other community supports. To date, many of the 30 dedicated beds have been filled with individuals who have graduated from Second Chance. The housing providers have done an excellent job supporting the patients in the community and continue to teach the community living skill in vivo that were reinforced in the inpatient setting.

We are currently discharging the patients through the SPOA system, mostly in New York City, competing with other hospitals for limited openings in the com-

munity residences. Initially there were regularly scheduled meetings with OMH, NYPH-PWW, and the housing providers to discuss the newly developing working relationships and to facilitate a better understanding of the special needs and perspectives of the partners. There was genuine excitement and enthusiasm amongst the partners embarking on this new relationship, and a trust developed as we worked together in the service of providing the best transition for the patients whom had been institutionalized for many years.

Andrew Bloch has been the liaison between Second Chance, OMH and the housing providers since the program opened its doors, and having one contact as the “point person” has facilitated the smooth transition of patients from one level of care to another.

Housing providers find working with Second Chance advantageous from several perspectives. They know that the patients being referred have been through a comprehensive rehabilitation program that maximizes the acquisition of community living skills. They also know that the patients have been stabilized on a medication regimen that best addresses their psychotic and affective symptoms while minimizing troubling side effects. The housing agency gets “credit” toward their requirement for taking state hospital patients, when they take a Second Chance patient. Our patients are also eligible for NY/NY III status through the New York City Human Resources Administration. The agencies work closely with Second Chance to have someone readmitted to the hospital for stabilization if that should be required. This provides a supportive safety net for the housing agencies when working with individuals with such challenging difficulties.

Establishing these partnerships between the inpatient setting and the housing providers has clearly been beneficial to the consumers of these services. On occasion a clinician from Second Chance has been asked to consult with a particular residence to strategize together on how to use some of the behavioral interventions at the residence as they attempt to address troublesome behaviors effectively. Unfortunately, limited resources of time and personnel do not allow for this potentially very useful service to occur often. It would greatly benefit the consumers if there could be even greater coordination of the treatments being used across treatment settings, from inpatient, to residential and day treatment programs.

It remains a curious phenomenon that while some of the best evidence on treatment effectiveness involves rehabilitative treatment of seriously mentally ill persons; these interventions are rarely used outside of academic medical centers. Creating a system wherein evidence-based interventions are used across the continuum of care for individuals with disabling psychiatric conditions would have major public health and financial benefits, including lowered relapse rates. It is, therefore, an extremely important next step to dedicate monies to the training and supervision of staff at both the housing

see Second Chance on page 30

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Internet Distance Learning Initiative Focuses On How to Treat Co-Occurring Mental Health and Substance Use Disorders

By Nancy H. Covell, PhD
and Paul J. Margolies, PhD
Department of Mental Health Services
and Policy Research, New York State
Psychiatric Institute

The New York State Office of Mental Health (OMH) funded Evidence-Based Practices Technical Assistance Center (EBP-TAC) at New York State Psychiatric Institute (www.nyspi.org/ebptac) is introducing a distance learning initiative that focuses on evidence-based integrated treatment for co-occurring mental health and substance use disorders. In 2007, 5.4 million adults in the U.S. had a co-occurring mental illness and substance abuse disorder, yet only 10% received treatment for both.⁵ The remaining 4.9 million faced increased re-hospitalization, homelessness, incarceration, violence, economic hardship, and infectious diseases, leading to higher treatment costs and family burden.³ Evidence-based integrated treatment for COD mitigates these risks by reducing substance use,^{2,3} which leads to lower treatment costs and promotes individuals' recovery, independent living, and employment.^{1,4}

In November of 2009, the Center will begin offering online training modules, webinars, and supports designed to help

practitioners, clinical supervisors, and agency managers and administrators implement integrated treatment in their settings. Funded jointly by the New York State Office of Mental Health and Office of Alcoholism and Substance Abuse Services, the distance learning initiative will offer 35 online modules that can be accessed from any internet location, at any time of day. These highly interactive and engaging modules, built collaboratively with partners at Dartmouth, will include recovery stories, presentations by experts, interactive exercises, panel discussions by experienced practitioners, clinical vignettes, and links to additional resources. Additionally, distance supports, in the form of online practice improvement networks, will offer webinars, "ask the expert" opportunities, and discussion threads to assist practitioners, supervisors, and agency leaders with implementation.

The advantages to distance learning are many, particularly in this lean fiscal climate. First, practitioners do not have to leave the office for extended periods to obtain training. This saves both practitioner time and dollars that would be spent reimbursing travel or paying for clinical coverage. Second, there are no cancelled trainings (e.g., for weather) that would ordinarily result in lost resources. As noted above, practitioners can log in to complete each 30-minute module any

time and from any location that has internet access. Third, with the modules designed each to be just 30 minutes, practitioners should be able to fit the training more easily into their busy day (e.g., when a client cancels an appointment). Fourth, information from training remains available to practitioners continuously. Practitioners can log into the system, relaunch any completed module, and use the menu to navigate to any area of interest. Fifth, practitioners, supervisors, and agency leaders have 24 hour access to electronic copies of important documents (e.g., screening forms), links to internet resources (e.g., videos produced by SAMHSA demonstrating how to run groups for co-occurring disorders), links to online discussion threads, and links to ask the expert forums. Finally, new staff can be trained immediately and consistently. In addition to these benefits, the learning management system that houses the modules maintains transcripts for each individual and allows agencies and other leaders to see who has completed training and to generate summary reports in a number of flexible ways (e.g., individually, by program, by agency, by degree or certification type, by job title, by region, by county, by licensing agency).

We are excited about the early enthusiasm from programs about this distance learning initiative and are looking forward

to evaluating and refining the approach as it rolls out. If you would like to learn more about the NYSPI EBP-TAC Distance Learning Initiative, please contact Nancy Covell, Ph.D., Project Director, at (covelln@pi.cpmc.columbia.edu).

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¹Fenton WS, Blyler CR, Heinssen RK. Determinants of medication compliance in schizophrenia: empirical and clinical findings *Schizophr Bull.* 1997;234:637-651.

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Schizophrenia Management As Part Of Home Health Care

**By Lisa Marie Sioufas, LCSW-R, ACSW
Mental Health and Social Work
Program Manager
Visiting Nurse Services in Westchester**

The World Health Organization has identified schizophrenia as one of the ten most debilitating diseases affecting human beings. Schizophrenia is comprised of several symptoms. Symptoms of this illness can also be found in other mental illnesses. However, when “the symptoms of schizophrenia have been present for a significant portion of time during a one month period (or shorter if successfully treated), with some signs of the disorder persisting for at least six months and is not better accounted for by Schizoaffective Disorder or a Mood Disorder with psychotic features, and the symptoms are not due to a physiological effect of a substance or general medical condition”, then a diagnosis of Schizophrenia can be made (DSM-IV-TR, 2000 pg 298-299).

The symptoms of schizophrenia typically are divided into three categories: positive, negative, and cognitive symptoms. Positive symptoms, or psychotic symptoms, include delusions, catatonic behavior and hallucinations. Positive symptoms refers to having symptoms that should not be there. Negative symptoms include affective flattening or lack of expression, avolition or an inability to initiate and follow through with activities, aloia or speech that is brief and devoid of content. Negative symptoms refers to a lack of certain characteristics. Cognitive symptoms refers to thinking processes. This is frequently exhibited in lack of organization in their thoughts and in lack of insight. (DSM-IV-TR, 2000 pg 297-302; National Alliance on Mental Illness www.nami.org, schizophrenia fact sheet)

Although incurable, schizophrenia is treated and managed with medications and a variety of therapeutic approaches. The primary medications for schizophrenia are called antipsychotics. Antipsychotics help relieve the positive symptoms of schizophrenia. Newer antipsychotics reduce the



positive symptoms such as hallucinations and delusions, but also relieve the negative symptoms of the illness, e.g., withdrawal, disorganized thoughts, and lack of insight.

People with schizophrenia often benefit from continuing day treatment programs. Substance abuse counseling, vocational skill development, employment and appropriate housing are essential to helping the individual with schizophrenia assimilate into the community and function at their optimal level. Peer mentoring and support groups are also helpful for people with schizophrenia and their families.

Recovery and remission in schizophrenia is receiving increased attention. Many researchers are looking at recovery not from a consumer perspective but from a clinical perspective. Researchers are trying to quantify recovery and remission in schizophrenia utilizing scales which measure symptoms and functional ability. Measuring the severity of both positive and negative symptoms and functional ability is thought to be key in establishing criteria for clinical remission.

Building a life in the community is part of the recovery process. A goal of all treatment is for individuals to be active members of the community. In order for

this to be accomplished it is important to identify a person's strengths, capacities, preferences and needs, as well as, their knowledge of their local community, its opportunities, resources and potential barriers. This will enable the individual to find their niche in the community in which they reside.

Patient independence and the ability for the patient to recover at home are among the primary objectives at Visiting Nurse Services in Westchester. VNSW's services allow individuals with all levels of mental illness the ability to remain in their homes and involved in the community mental health programs that are an integral part of their treatment. The agency's ability to monitor psychiatric symptoms and medication compliance – in addition to teaching the skills needed by each individual to help manage their specific psychiatric needs – empowers patients to obtain their optimal level of independent functioning/living. VNSW's nurses regularly observe individuals in their homes, enabling the agency to provide feedback to caseworkers on the appropriateness of the patients housing and often to assist in obtaining housing with increased or decreased supportive services. VNSW nurses have the ability to

help the patient advocate for their desired needs as they see the person in their environment and are well aware of their needs and ability to remain safely in their homes. The nurse can often intervene with symptom management before problems reach a level requiring hospitalization, thus enabling patients to remain at optimum level of function, with minimal interruption.

At Visiting Nurse Services in Westchester, patients are considered partners – the agency works together with patients toward recovery and reaching a maximum level of independent functioning. The staff supports and encourages patient independence and its services strengthen care coordination. VNSW's mental health program is an important adjunct service to community mental health services. The program provides daily visits 365 days per year, if needed. VNSW works collaboratively with the patient, supportive and intensive case managers, and the agency's flexible visitation schedule is designed to accommodate patients' day treatment attendance. VNSW's nurses offer their patients support and monitoring to ensure success by offering an individually tailored care plan to meet each person's needs as they arise, before they reach crisis levels.

In addition to nursing care, VNSW provides a full range of rehabilitative therapies, social work and home health aide services; psychiatric patients receive comprehensive care from a coordinated team of health care professionals versed in, and sensitive to, their complete history and needs, providing a complete package of essential multidisciplinary services to help them, following a hospital discharge, to attain and maintain optimal health and functioning in their communities.

With its dedicated Mental Health Home Care Program, Visiting Nurse Services in Westchester is achieving this objective, emphasizing treatment of the whole person with the agency's core multidisciplinary approach. For details, visit www.vns.org, call (914) 682-1480 Ext. 648 or e-mail MentalHealth@vns.org.

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Research Project from page 7

Medical Research, Manhasset, N.Y. The second group will be led by Jeffrey Lieberman, M.D., of the Research Foundation for Mental Hygiene, Inc., New York City. The research teams feature national and international collaborations, with treatment to be delivered in up to 30 clinical sites across the United States.

Recovery Act funds will underwrite the initial two phases of the trial, during

which the investigators will refine the interventions with input from stakeholders and conduct a feasibility study to demonstrate that each intervention can be fielded in real world community treatment settings and be evaluated in a randomized clinical trial design. With long-term funds committed by NIMH to complete these phases plus a full-scale clinical trial, funding for the study is \$40 million.

“Depending on the study's outcome, RAISE could help set the stage for a

paradigm shift in the way schizophrenia is treated in the United States. The ultimate goal of the initiative is to eliminate the chronic form of schizophrenia that is so costly and devastating to the individual, family members, and society as a whole,” said Robert Heinssen, Ph.D., acting director of the NIMH Division of Services and Intervention Research and project officer for RAISE. “This Recovery Act-supported project will hire and help train many mental health research-

ers and care providers for a project that is likely to help some of our most vulnerable citizens lead more productive and satisfying lives.”

NIMH is using Recovery Act funds to carry out objectives identified in its Strategic Plan. Among these objectives is to develop new and better interventions that incorporate the diverse needs and circumstances of people with mental illnesses and to strengthen the public health impact of NIMH-supported research.



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- Facilitate psychiatric care from in-patient to home & community
- Prevent in-patient psychiatric hospitalization
- Decrease symptoms & improving functional ability
- Improve knowledge base about medications, illness, coping & staying well
- Improve medication compliance
- Access community services

The Big Picture

Visiting Nurse Services in Westchester (VNSW) believes in a holistic, broad approach to the treatment of mental illness, addressing the "whole person's" life circumstances and environment. VNSW fields nurses with advanced psychiatric training, and in some cases, advanced degrees in related fields. The staff provides home visits for assessment, evaluation and development of a treatment plan with interventions related to mental health issues in conjunction with medical/surgical needs. This program meets the total health care requirements of individuals utilizing a case management approach led by a psychiatric nurse specialist. Adjunct services complementing the mental health component include psychiatric social workers, home health aides, medical/surgical nurses and relevant rehabilitation therapies.

The program serves the elderly, adults, adolescents and children.

To receive further information or make a patient referral, contact:

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Social Security: Dispelling the Myths

By Tom O'Clair
Recipient Affairs Specialist
Family Issues
NYS Office of Mental Health

Very often in the human services field we encounter people who want to help but just are not equipped. Their desire to make a difference in another's life or situation prompts them to pass on bits of information that they themselves have learned, experienced or heard. As often happens in the casual transfer of information, something gets lost in the translation. It is due to this fact that myths often occur and in that occurrence people believe them to be fact. The intent to help can some time become a hindrance because of information that has no factual basis.

When we give the "Social Security Myths Tips Tricks and How to Make It Work" trainings, the first thing we say is, "If someone tells you something concerning Social Security, ask them to show you the documentation." When it comes to Social Security, accurate information is essential in positively affecting another person's life when that person is, more often than not, living below the poverty level. We quote Social Security's documents when we do these training and provide the attendee with the actual SSA forms and tell them where they can find the

actual statute. We want the providers, consumers and family members who attend our trainings to be as informed as possible so as to streamline and make positive their experience with the Social Security system, and to assist others in getting away from the myths that have made them afraid to try to succeed. So many have been afraid of what they have heard that has absolutely no solid fact or basis.

One of the biggest myths is that people on benefits can't work or they will lose their benefits. How scary is that for someone who wants a purpose to their life but hears "you can't or else"? The fact of the matter is, the Social Security Administration actually wants people to be able to work so that they may reach a level of ability that would allow them to become self sufficient. If they can become self sufficient, they can then contribute back to the system by working and paying taxes. We cannot tell you how many people have said to us over the past few years, "I can do that? I can really go back to work without risk to my benefits my well being?" (They actually become very excited and enthusiastic) or "How come I have been told all of this time I cannot work?"

Yes! You can go to work or back to work. The Social Security Administration has developed a number of work incentives to make this possible. In fact, most of these incentives have been present in the system for many, many years. People have-

n't known about them because they haven't had the need or desire to research them, sometimes it's easier to just believe what you're told. To quote the SSA Red Book, "One of the biggest concerns SSI beneficiaries have about going to work is the possibility of losing Medicaid coverage."

To further quote the Red Book, "Medicaid is a jointly funded, Federal-State health insurance program for low-income and needy people. It covers children, the aged, blind, and/or disabled and other people who are eligible to receive federally assisted income maintenance payments."

Thirty-two states and the District of Columbia provide Medicaid eligibility to people eligible for Supplemental Security Income (SSI) benefits. In these States, the SSI application is also the Medicaid application. Medicaid eligibility starts the same months as SSI eligibility.

What happens to Medicaid coverage if a SSI recipient works? If a recipient's State provides Medicaid to people on SSI, the recipient will continue to be eligible for Medicaid. Medicaid coverage can continue even if a recipient's earnings along with other income become too high for a SSI cash payment.

How does a recipient qualify? To qualify a recipient must: (1) Have been eligible for an SSI cash payment for at least one month; (2) Still be disabled; (3) Still meet all other eligibility rules, including the resources test;

(4) Need Medicaid in order to work; and (5) Have gross earned income that is insufficient to replace SSI, Medicaid, and any publicly funded attendant care.

One of the most exciting programs the SSA has to prevent this is Continued Medicaid Eligibility or "1619b". Section 1619(b) of the Social Security Act provides some protection for these beneficiaries. To qualify for continuing Medicaid coverage, a person must: (1) Have been eligible for an SSI cash payment for at least 1 month; (2) Still meet the disability requirement; (3) Still meet all other non-disability SSI requirements; (4) Need Medicaid benefits to continue to work; and (5) Have gross earnings that are insufficient to replace SSI, Medicaid and publicly funded attendant care services.

This means that SSI beneficiaries who have earnings too high for a SSI cash payment may be eligible for Medicaid if they meet the above requirements. SSA uses a threshold amount to measure whether a person's earnings are high enough to replace his/her SSI and Medicaid benefits. This threshold is based on the: amount of earnings which would cause SSI cash payments to stop in the person's State; and average Medicaid expenses in that State.

If a SSI beneficiary has gross earnings higher than the threshold amount for his/her State, SSA can figure an individual

see Myths on page 37

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Living with Schizophrenia: A Sister's Perspective

As Told to and Written By
Judith H. Cohen, PhD, JD

Aaron* was born in 1950 and was diagnosed with paranoid schizophrenia at age 17. Everyone thought that Aaron was a difficult child. He had tantrums and rages from a young age, but he seemed very intelligent although he had trouble succeeding in school. Aaron had seen many psychiatrists and psychologists during his teen years and was in and out of hospitals and group homes for the mentally ill as a young adult. Nothing seemed to help him. He had terrible side effects from his medications, became a chain smoker, gained lots of weight, became violent at times and continued to suffer from paranoid delusions. He died from unknown causes at age 36 after walking out of the mental health unit of a metropolitan hospital. He was reported as a Missing Person by the family, but his body was not identified until several months later. Evidently, he died on a subway train soon after leaving the hospital, and his body was sent to the city

morgue. Aaron had "disappeared" many times before and his mother and sister expected that he would eventually contact them but when the identification of the body was made, they were traumatized by the manner of his death.

Aaron's immediate family consisted of his father, mother, and younger sister, Sharon. His father was a victim of the Holocaust, had survived concentration camps in Poland and was a witness at war crime trials in Germany. He came to this country after the war with one brother, married and had the two children. He was not a handsome man and had low self esteem due to his appearance, but had bright blue eyes, a fast wit, resiliency and a burning ambition to get ahead in this new country that he loved. At some point in middle age, the Father began to see a psychiatrist because of his bipolar behavior and extreme mood swings. He deteriorated with severe depression during Aaron's early adolescence due to the death of his own brother from leukemia. He would sit crying endlessly rocking back and forth in a chair. No one in the family could understand this behavior, nor were their attempts to help him successful. One

day he disappeared and his body was found hanging in a public garage an apparent suicide. During his life in the US he became a very successful, business owner and was well-regarded in his community.

Aaron's mother was a difficult individual whose married life was fraught with problems that couldn't be solved and only got worse. In her early years she thought she'd become a career woman especially given her employment during WW II, but eventually she married. In the early years of her marriage her problems resulted from her husband's bi-polar episodes and her son's unmanageable behavior. Her life was made terribly worse when her husband committed suicide. She tried to do all that she could for her son and daughter and even took them on a European vacation and moved to a different neighborhood. When her son was diagnosed with paranoid schizophrenia her life was never the same. Although left with financial resources at the time of her husband's death, the money declined through the years due to the cost of repeated doctors and hospitalizations for her son, no employment by herself and her daughter, and her losses in the stock market. Playing the

market became her passion and Sharon thinks that it was one of the few things in mother's life that made her feel good. For many years after her husband and son died she lived a simple life with her daughter in an urban apartment surviving only on her social security. She was estranged from her extended family and died when she was in her 80's.

Sharon felt that she had a wonderful childhood. She admits to having been a spoiled child and remembers that her brother was always difficult. Then her father died. She was told he had a heart attack, but she always suspected that there was a secret about the death that was not shared with her. When her brother's illness took hold of the family a few years after her father's death, her life became isolated and fearful. She, her mother and brother moved from their private home near her father's business and relocated to an apartment in a different, middle-class part of New York City. Everyone in the family thought that this move would give them a fresh start. Sharon believes she suffered a nervous breakdown when she

see Perspective on page 30

The Burden of Caring For a Family Member Diagnosed With Mental Illness

By Oren Shtayermman, PhD, MSW
Assistant Professor of Mental Health
Counseling, New York Institute
of Technology

According to Hare (2004), person-in-environment is a core concept in social work. This concept views individuals and their environments as active and interactive structure, in which each part concurrently influence and is affected by other. This concept is also the preferred methods of treatment for individuals and their families. Weiss-Gal (2008) argued that there are very few studies examined the integration of this approach into practice. Social Workers who are treating individuals diagnosed with mental illness and their families should take into consideration the

impact the illness has on parents and siblings (VanBergeijk & Shtayermman, 2005). There is a need to develop a better understanding of the often invisible difficulties that caretakers face in their daily living with an individual diagnosed with mental illness (Jarvis, 2006).

Family Burden: A considerable amount of research was conducted and documented the level of stress associated with caring for an individual diagnosed with mental illness (Shankar & Muthuswamy, 2007). The concept of burden, as experienced by family caregivers, originally developed in United Kingdom in the 1960s in response to the deinstitutionalization of individuals diagnosed with mental illness. Physicians were concerned that patients treated in the community setting would be too much of a burden on families. The concept of burden

was defined as "how much effect" the patient's illness had on family income, employment, leisure activities, domestic routine, children in the home, health of household members, and relationships with neighbors as judged and rated by an interviewer (Worcester, Archbold, Stewart, Montgomery & O'Connor, 2003). According to Hoening and Hamilton (1966) there are two types of stress associated with caregiving. The first type of stress is referred to as subjective burden. This burden refers to the feelings, attitudes and emotions that result from the caregiving experience. Objective burden is defined as the concrete events and activities related to the actual provision of assistance (Rose, Bowman, O'Toole, Abbott, Love, Thomas & Dawson, 2007).

Supporting Family Members: Evidence suggests that a large measure of the

stress experienced by caregivers may be associated with the lack of essential support such as crisis information, support services, skill development and caregiver counseling (Shankar & Muthuswamy, 2007). Approaches to working with families who are caring for an individual diagnosed with mental illness all have a diverse blend of emphasis however, common characteristics include: information about mental illnesses, teaching and facilitating problem solving, emotional and practical support.

Oren Shtayermman, PhD, MSW, is an Assistant Professor of Mental Health Counseling, and Mental Health Counseling Program Coordinator - OW Campus. He is Research Associate to VIP at the New York Institute of Technology School of Health Professions, Behavioral and Life Sciences, in Old Westbury, New York.



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Can You Trust the Research Findings You Read On The Internet?

By Irene S. Levine, PhD
and Jerome Levine, MD

There's always a new report hyping one type of health discovery or another. The results usually sound promising, or else they wouldn't be newsworthy, but can you really believe everything you read on the Internet? Another case of caveat emptor or let the buyer beware—even if the information is free!

In some cases, these reports herald real advances that redefine what we know about a disease. But too often, the findings we hear about from the media come from preliminary studies, conducted with small numbers of people, that haven't been verified by other researchers. Yet if you or someone you love is suffering from a rare, serious, or hard-to-treat disorder, these reports offer a glimmer of hope for the future.

If you're struggling with schizophrenia, you are just as likely to be bombarded with dubious information as you would for any other medical condition. While scientists have learned a vast amount of information about diseases of the brain, including major mental disorders, much more still remains to be learned. Research is generally a slow, incremental process, where one scientist's finding builds upon another's. Additionally, there are often long lapses between the time research is conducted in a labora-

tory and the time findings are implemented in clinical practice.

In the best of all worlds, through continuing education, staff development, supervision, and staying on top of relevant resources, treatment professionals would keep abreast of all the research developments in the field that may prove beneficial for their patients' care. But that isn't always the case. So it falls upon service recipients and family members to improve their own "mental health literacy" and stay informed so that they can ask the right questions to obtain the most effective treatments and care.

Fortunately, rapid advances in technology have enabled anyone with access to a computer or to a library to perform information searches on their own. Who among us hasn't succumbed to the temptation of turning to the Internet for self-diagnosis or to second-guess a doctor for a condition as innocuous as a hangnail or something as serious as an inoperable cancer?

Web sites, user groups, wikis, and social networking sites (like Facebook, MySpace, LinkedIn and Twitter) can all provide useful and interesting information (as well as distraction) but embarking on the information highway requires discretion, judgment and caution. Here are some tips and things to think about from our book, *Schizophrenia for Dummies*, which may be useful in guiding you towards accurate and unbiased information and evaluating what you read:

Be critical of what you read

- Anyone can say anything on the Internet
- You do not always know who has posted the information
- There is no assurance of the accuracy or quality of the information you see
- It may be difficult, if not impossible, to differentiate fact from opinion

Consider the source of all information

- Try to stick with sites sponsored by reputable organizations. The URL can often help you identify the source of the information (.edu, .gov, .com, .org, .US, etc.).
- Be wary of commercial sites that are selling products
- Examine the references at the end of an article. Try to determine the credibility of the author or editor of the information by looking at their credentials and affiliation
- Find out the source of the information you're reading. Was it derived from a clinical trial, experience, or is it simply an opinion?
- When possible, try to utilize sites that are grounded in evidence-based medicine, which is based on solid research

- Compare information on the same topic from different sites to see if they provide similar advice
- Be especially cautious about testimonials you find on bulletin boards or in chat rooms. More often than not, they represent subjective opinions, rather than facts based on medical research

Make sure information is current

- Every major page of a web site should include the date that it was written or reviewed.
- Whenever possible, rely only on material that includes a date. On some sites, no one verifies whether information is still accurate or whether it became obsolete long ago

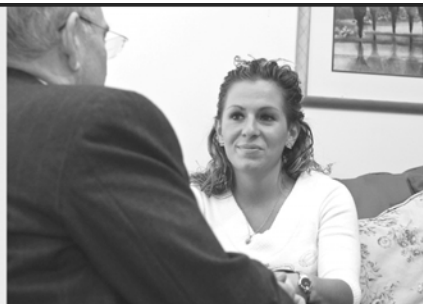
Make sure the arrangement of material on the site is user-friendly

- There are many, many sites to choose from: so be sure to use those that are easy to read and navigate.
- Don't waste your time trying to find information embedded in poorly designed web sites

Remember that the Internet cannot substitute for medical advice

- Given all the caveats discussed

see *The Internet* on page 37



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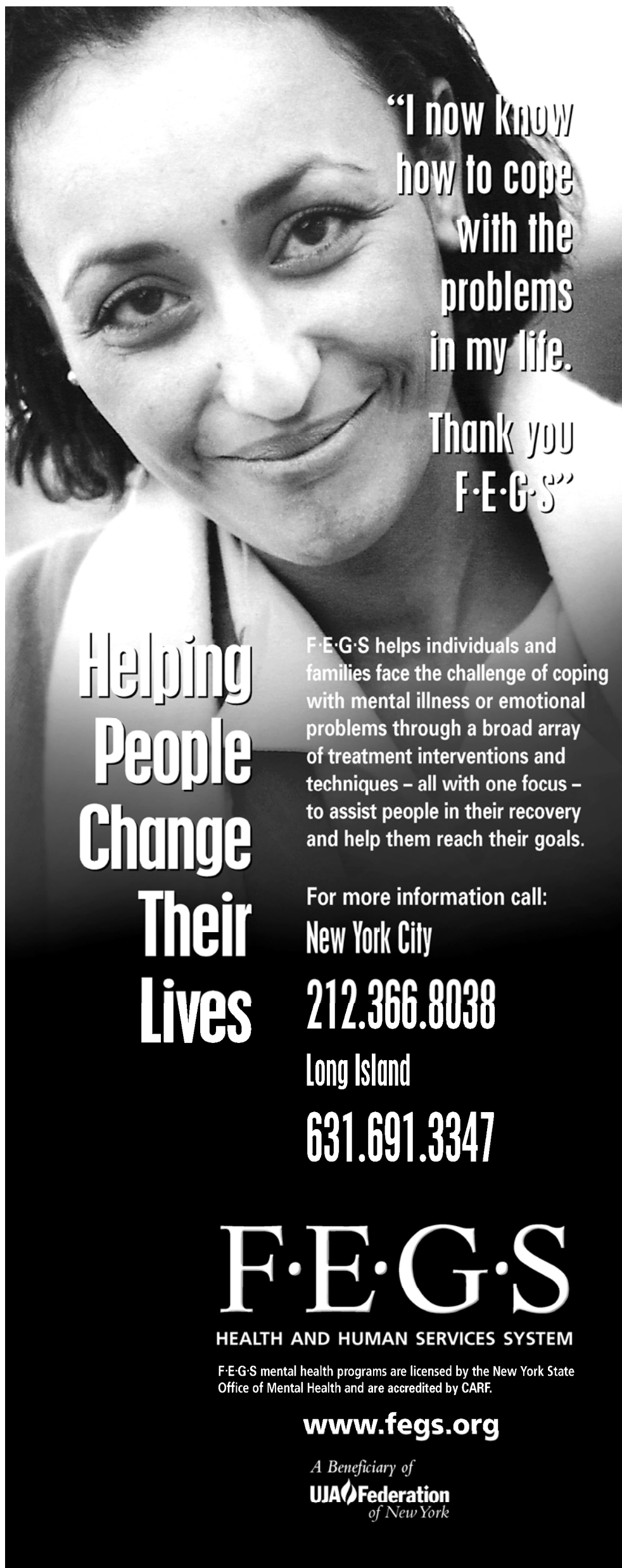
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Unraveling the Story: Active Listening Requires Active Asking

By Ellen Stoller, Assistant Vice President Professional Development and Consumer Affairs, and Gerardo Ramos, Assistant Vice President, Community Residences and Homeless Services, F·E·G·S Health and Human Services System

Donald (not his real name) is a 53 year old, single African American man diagnosed with Major Depressive Disorder with severe psychotic features. He has one child who he is estranged from and seems to have no other living family members.

Sometimes the kind of scant information above is almost all we know about a consumer. Take Donald for instance. He doesn't talk much and when he does his speech is hard to understand. Donald resided within the NYC shelter system from 1987-2004, 17 years. He had a three year stay at a community residence but in 2007 he went back to the street. He thought his life would be better in the residence but it wasn't. He never felt he got the services he needed, he felt isolated and unappreciated.

What made it so hard for Donald to get help? At an earlier time Donald had been diagnosed with schizophrenia, then major depression with severe psychotic features. Does a diagnosis sometimes seal your fate? Maybe because he was hard to understand people thought he had nothing to say. Maybe he wasn't articulate about his needs, wants and desires. Maybe he was never asked. Maybe most people thought he would never amount to much and he thought that too. We don't know, but eventually Donald found his way to the FEGS-VOA program (an on-site rehab program run by FEGS in the VOA shelter on Wards Island for homeless people who have a mental illness) and things started to change for him. He was admitted into the program, evaluated by the psychiatrist and assigned to a case manager who began to work with him on steps that would enable him to live safely in the community and become a productive community member.

Donald's FEGS/VOA case manager worked diligently with him on his medication management objectives. His case manager looked for him in the mornings and afternoons to remind him to take his medications. The program's nurse also played a pivotal role in assisting Donald by explaining the benefits of taking his medications as prescribed. As a result of the combined collaboration and commitment of the nurse and case manager, Donald came to believe that by taking his medication, he would increase his own ability to become permanently housed – his goal. He might not have to be in the hospital again either.

Donald was also counseled on the importance of attending the various groups the on-site rehab program offered including groups that focused on: sub-

stance abuse, housing, money management, socialization, and setting vocational goals.

Staff from the FEGS Housing Central Intake Unit met with Donald after he was assigned to FEGS-VOA. Donald reported that he was sad and depressed and felt cut off from the world. More interestingly, he shared that prior workers at various shelters did not take the time to listen to him. As a result of this statement it was evident that Donald needed to be heard and in fact had a lot to say. Because his speech is slurred and he is difficult to understand it requires patience to understand him clearly. With this in mind, the team convened to discuss the client's needs and the ways that they could be more responsive in their approach to help him obtain permanent housing. The team surmised that Donald remained in the shelter for nearly two decades partly because of his inability to verbalize his thoughts and needs clearly. The more frustrated Donald would get in not being understood the more emotional and disturbed he seemed and the more staff avoided him. Being ignored made Donald angry and his behavior became more aggressive. It was a vicious cycle.

The team encouraged Donald to attend community meetings. The aim of this approach was to provide him with a forum where he would be able to express his thoughts and feelings, and to use his developing communication skills in a safe and structured environment – thereby minimizing his feelings of isolation. Consequently, Donald began to speak more confidently; his thoughts were lucid and this lessened his emotional eruptions. Additionally, Donald was identified as a candidate for the Work Incentive Program. He was interviewed and was hired shortly after being in the program. The WIP helped Donald in several ways including building his self-esteem, providing the opportunity to further work on his socialization skills, and provided Donald with some structure in his life, and an identity as a working person.

There are many stories of people who have a long history of mental illness whose needs are not met. It would have been easy to not listen to Donald; he was hard to understand, aggressive, and seemed to be an unmotivated long term shelter system client. However, the FEGS/VOA staff knows that trying to unravel why a person has not been successful in the past can open new doors; they took the time to figure out Donald's story and they have helped him write a different ending. Donald has moved out of the shelter into a community residence, the next step, his own apartment and a job. Who knows how far he can go?

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Ways of Looking from page 1

memory we use especially when we are attempting to concentrate on a task and use information we have learned.

Dysfunction

Some of these thinking problems are also found in people who are depressed, or who have Bipolar Disorder, even when they are not acutely ill. But the problems for persons who have schizophrenia are, in general, more pronounced and persistent. This does not mean that persons with schizophrenia can never make decisions, or plan activities, or complete tasks. Dysregulation implies that these functions are harder for the affected person, which tends to produce discouragement and withdrawal, and lack of effort. And effort can be influenced by a variety of factors, both psychological and physical. One of the critical things we have learned – though it is information that is unfortunately often not put into practice – is that too much of the type of medication that is useful in decreasing agitation and hallucinations (antipsychotic medication) can make these thinking problems worse, so that the right amount of medicine, generally, is that which minimizes the side effects the medicine can cause.

The changes in thinking processes I have described, which represent malfunction in some brain circuitry, produce what is termed executive dysfunction, because they are processes necessary to the brain's ability to "execute" orders – to produce thoughts and behaviors – and involve specific areas of the brain, especially the pre-

frontal cortex², and related structures, which are constantly operating as we think, without our awareness. When they are not working, we find ourselves confused, stymied, and prone to misinterpret what is happening around us.

Advances in research have illuminated much about the nature of the illness – though there is much more to learn – that will undoubtedly lead to better treatments. Clinical research has also helped us to understand more about why medications work, how and when to use them, so that the experience of taking medication is more comfortable and rewarding for most individuals than it was when I first studied psychiatry. I still remember sober researchers, and senior colleagues, insisting that high doses of antipsychotics should be used until delusions³ were eradicated. Following that advice really meant raising doses until the person stopped talking, either because they realized the consequence of mentioning their beliefs, or because the medication simply "froze" their thinking.

Inspiration

Toward the end of my training I remember two very different, but equally critical events, each of which changed the way schizophrenia was treated and understood. Research on the unique effectiveness of clozapine was then released, and showed that persons who had not previously responded to other medications could be helped for the first time. Though clozapine did not work for everyone, it led to the development of other medications that have greatly expanded options

for health care providers and their patients. More importantly, the fact that clozapine worked differently than other medications helped to invigorate research on the physiology of the illness. In consequence, new insights have been made possible.

We know so much more now, for instance, about the nature of the disorder, as described previously, that the phrase "chemical imbalance," once used to describe what was thought to be wrong in the brain, is justly and finally seen to be unhelpful, inaccurate and out-of-date. Rather than dealing with a simple excess, or deficiency, of a neurotransmitter (a "chemical," in a sense, though the word has always seemed to me somewhat dehumanizing), we instead see that dysregulated brain circuits cause schizophrenic symptoms. There may be, in consequence, reduced or elevated activity within some pathways that rely on particular transmitters (egs. dopamine, or glutamate), but it is due to altered communication in a very complex system. Neurons manufacture their own neurotransmitters, and determine the amount they produce after "reading" their environment, trying to determine how much activity is going on around them, by "deciphering" instructions from the thousands of nerve cells sending them information. There are thus multiple concurrent influences on neuronal activity that affect behavior, emotion and cognition, and in turn the response of a given nerve cell can occur in a variety of ways. It may not be the absolute or relative amount of dopamine or glutamate that is abnormal, for example, but the timing of neurotransmitter release, the

frequency of its "pulses" of activity, or the presence or absence of co-transmitters; all occurring in the context of the simultaneous influence of other neurons and neurotransmitters on the target neuron.

While clozapine's advent itself encouraged me to be hopeful about my ability to help my patients, another research study affected me more than any other event in my professional life. Dr Courtney Harding had been searching for a suitable topic for her doctoral thesis in epidemiology at Yale University when she came across a forgotten study, published in the 1960's. Dr George Brooks, who authored the earlier study, had directed an innovative program through the Vermont State Hospital that, beginning in the mid-1950's, studied chronically ill patients in their hospital system who were provided with an intensive program of psychosocial rehabilitation. The patients, all of whom had had at best modest responses to medication (mostly chlorpromazine) were then moved into the community with equivalent support: case management, vocational support, assistance with community integration, and other services, as well as routine psychiatric care. When he published data after 5 years of follow-up, Dr Brooks found that approximately 70% of the patients had remained in the community, a truly remarkable achievement.

Dr Harding was curious about the longer-term outcome of those study patients and so contacted Dr Brooks, and arranged to revisit those patients 25 years after the original study had ended. What they found was astounding. Most of the

see Ways of Looking on page 28



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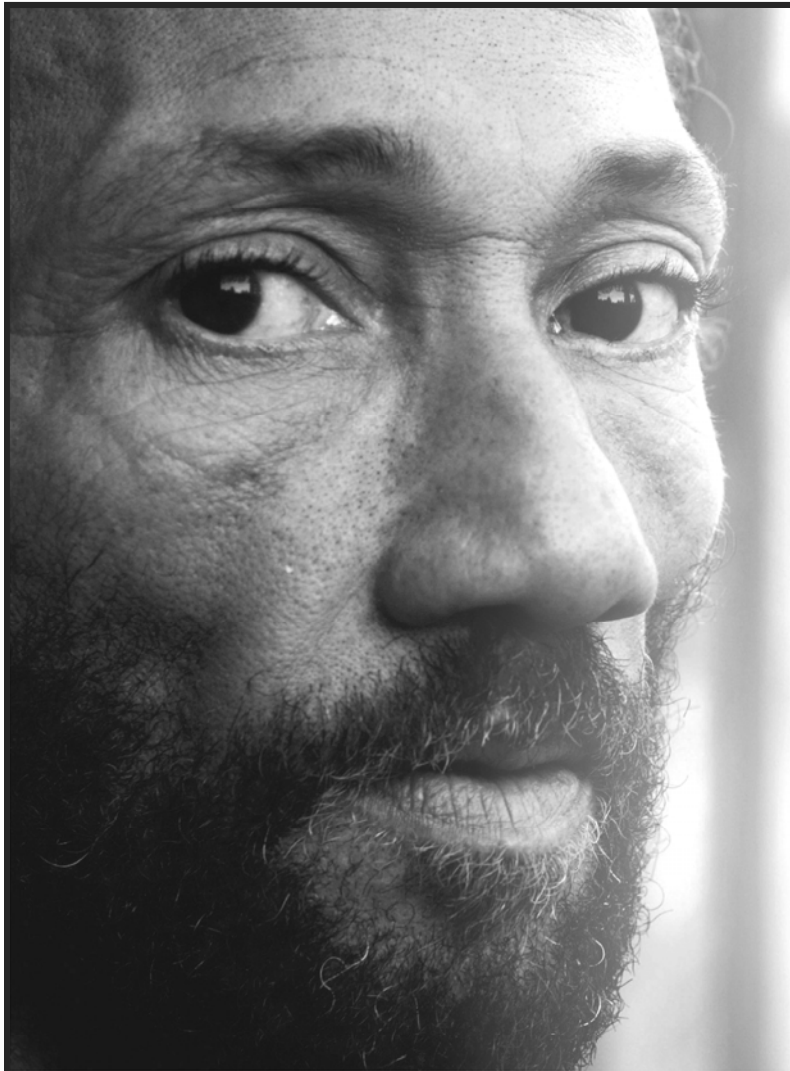
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Ways of Looking from page 26

study participants were still living in the communities to which they had been discharged many years before – Dr Harding used to quip that people in Vermont generally don't move once they get there. What was even more notable was that almost 2/3 of the individuals, who had initially entered the study after spending years on the “back wards” of the State Hospital, were rated as “considerably improved or recovered” by clinicians who did not know their histories.

When Dr Harding came to my hospital to present her research, she showed pictures of the study subjects, living in their communities, happy, and appearing well. She shared vignettes of their lives. I, as were many in the audience, was moved to tears. It was nothing less than a triumph of hope.

I began to read, avidly, the literature on recovery, immersing myself in ideas that were so full of promise, and so much in contrast to the dourness, aversion and pessimism I found when talking to many colleagues, and especially some mentors, about schizophrenia. And so I was surprised to read of another series of studies, conducted by the World Health Organization (WHO) under the research leadership of Dr Norman Sartorius. The study was initially devised to answer social critics of the time (Thomas Szasz, R.D. Laing and others) who maintained that schizophrenia was a severe form of social alienation, caused by the ill effects of Western industrialized cultures and economies. Researchers armed with culturally sensitive instruments visited communities across the globe, rural and urban, developed and developing, those with access to modern medical care and those without such access.

The International Pilot Study of Schizophrenia (IPSS), published in 1973, found that schizophrenia was roughly as common in developed as in developing countries, seeming to disprove the contentions of the social critics. But when the researchers also noted that outcomes in developing countries, where medical care was often lacking or at best rudimentary, were significantly better, on average, than in richer countries where most of the individuals were being treated by mental health care providers, and with antipsychotic medication, there was an uproar of protest. Not least the pharmaceutical companies cried foul, as did many academics who questioned the methodology of the research.

Recognizing that the original study had limitations, Dr Sartorius organized a follow-up study, which was eventually published in 1979. Supported by more detailed research tools, more data, and more numbers of individuals studied, the follow-

-up study revealed that the conclusions of the first study were true.

The conclusions of the researchers were not simplistic, and they did not maintain that antipsychotic medications were unnecessary or harmful, or that outcomes in developing countries were uniformly better. Writing in a recent review article (Schizophrenia Bulletin vol. 34 no. 2 pp. 253–255, 2008), Dr Sartorius and his colleague, Dr Jablensky, reiterated their earlier conclusions: that although their findings could not prove a cause for the observed differences, their studies suggested that “culture” was the most powerful independent variable; and that what appeared to be distinguishing about culture in developing countries was a trend toward social inclusion of the affected individual.

That is not to say that those societies were free of prejudice, or that persons with schizophrenia had ideal social supports. But it did appear to investigators that those societies were better at helping persons with severe mental illness to find a useful role in their communities. The affected individuals seemed to experience themselves as performing meaningful functions, and of having a meaningful place, not just within their family, but within the larger community.

It remains surprising to me how little these studies are discussed, how often medical students and residents who I teach say that they have never heard of them. And then I think about the amount of money pharmaceutical companies provide to medical schools to support research, and I become frustrated, and briefly sad. In truth, the lessons of these studies are no less a challenge to our society as a whole than to the mental health community, and demand of us much soul-searching and debate.

Implementation

We now enjoy an era of active attention to both the nature and etiology of schizophrenia, and to the development and implementation of “evidence-based” therapies, such as job coaching, “Housing First” residential programs, Assertive Community Treatment, and others. These treatments represent the fruition of the ideals, and models, of clinicians and researchers of an earlier generation, like those we have described above, who saw the value of having meaning and purpose in one's life, and realized that one of the most devastating effects of schizophrenia occurs when it steals that sense of purpose from the individual.

Though there remain severe gaps between the theoretical availability of effective treatment models, and their actualization, there has never been more support for good ideas, within communities, advo-

cacy groups – like the National Alliance on Mental Illness (NAMI) – and foundations – like NARSAD – than there is now. And governments have been more inclined to listen, sometimes persuaded that good care, though requiring initial investment, will eventually reduce costs.

And yet, there are signs of trouble. Our national, and global, financial crisis threatens the existence of precious treatment services, and has distressed the relationship between government and the healthcare system. New York State, in this context, has pressed forward with its long-promised PROS (Personalized Recovery-Oriented Services) initiative. The philosophy and principle animating that initiative is admirable. However, like many programs devised by government (though some groups of clinicians and consumers were invited to provide input, it is in the end a prescriptive regulation) it is burdened with requirements more likely attractive to an auditor rather than to those for whom it had purportedly been designed.

Instead of setting global budgets and outcome targets, and then encouraging creativity, PROS dictates small details of program design and operation, with demanding targets for documentation, which, if not met, even by earnest and dedicated caregivers, could, by violating compliance guidelines, put the financial viability of an entire organization at risk. The overall aim appears too heavily weighted toward cost control. The overall effect of such programs is often intimidating to caregivers, like being made to wear a futuristic robotic suit with profuse instructions: confining, awkward and not uncommonly frustrating, ultimately risking that laudable intentions may be rendered ineffectual.

Reflection

One of the advantages of having worked in my community for more than 25 years is that I now, often, meet former patients, many with a history of schizophrenia, on the street, in a movie theater, or restaurant, going about their daily lives. So many of them seem well, and happy, managing active lives, and no longer burdened by illness in the way they were when I first worked with them, that I am grateful to have been privileged to have worked with them, and to have seen their growth and success. They remind me of the contented people in Courtney Harding's presentation, their lives an active testimony to the reality of recovery, amid the healing presence of compassion, trust and hope.

So I suppose I am of three minds, after all, like the three blackbirds in the tree, from the poem I quoted at the beginning of this essay. I am sometimes in a proud

and rational mind, contemplating all we have learned, and can now use to the benefit of persons with schizophrenia. At other times I dwell in a mind of apprehension and frustration, preoccupied with the nearness of a good and just community, that could care for and heal those who are ill through no fault of their own, or anyone's; thinking that yet our communities are still so resistant to insight and change.

Finally, I come to what I can possess of wisdom, a mind that sees the human value of attempting to do what is right, in the face of obstacles, ignorance, mendacity, and greed; in which I join my labors to those of like, good people, for whom we should all be grateful, who quietly dedicate themselves to this work, in clinics, hospitals, and in our communities; and in which I, and we, stand with and for those whose hard journeys we support and honor, rejoicing in the dignity and purpose they reclaim from the clasp of despair. It is in that mind I choose to make my place.

Timothy B. Sullivan, M.D., is Clinical Chief of Services for the Seriously Mentally Ill, including the Assertive Community Treatment Team, WestCARES Program and Continuing Day Treatment Program, at St. Vincent's Hospital Westchester in Harrison, New York. He is also a clinical assistant professor of psychiatry at New York Medical College and is a Distinguished Fellow of the American Psychiatric Association. Dr. Sullivan has published in numerous journals and is co-author of the book, Working with the Person with Schizophrenia: The Treatment Alliance.

Footnotes:

1. “Dementia Praecox” was a term first used by Emil Kraepelin, a German psychiatrist of the late 19th and early 20th century, whose Textbook of Psychiatry was, and remains, enormously influential. Bleuler was the first to confidently assert, in opposition to Kraepelin, that “schizophrenia” was not a true dementia.
2. The prefrontal cortex is the area of the brain directly behind our forehead, and over our eyes. It is the area of the brain that is more developed in humans than in other primates.
3. Delusions are different than other psychotic symptoms, like hallucinations. They represent the mind's flawed attempt to make sense of the psychotic experience, to create a narrative. To eradicate them risks destroying what is essentially a compensatory process, an effort to create continuity, however imperfectly, out of chaos.



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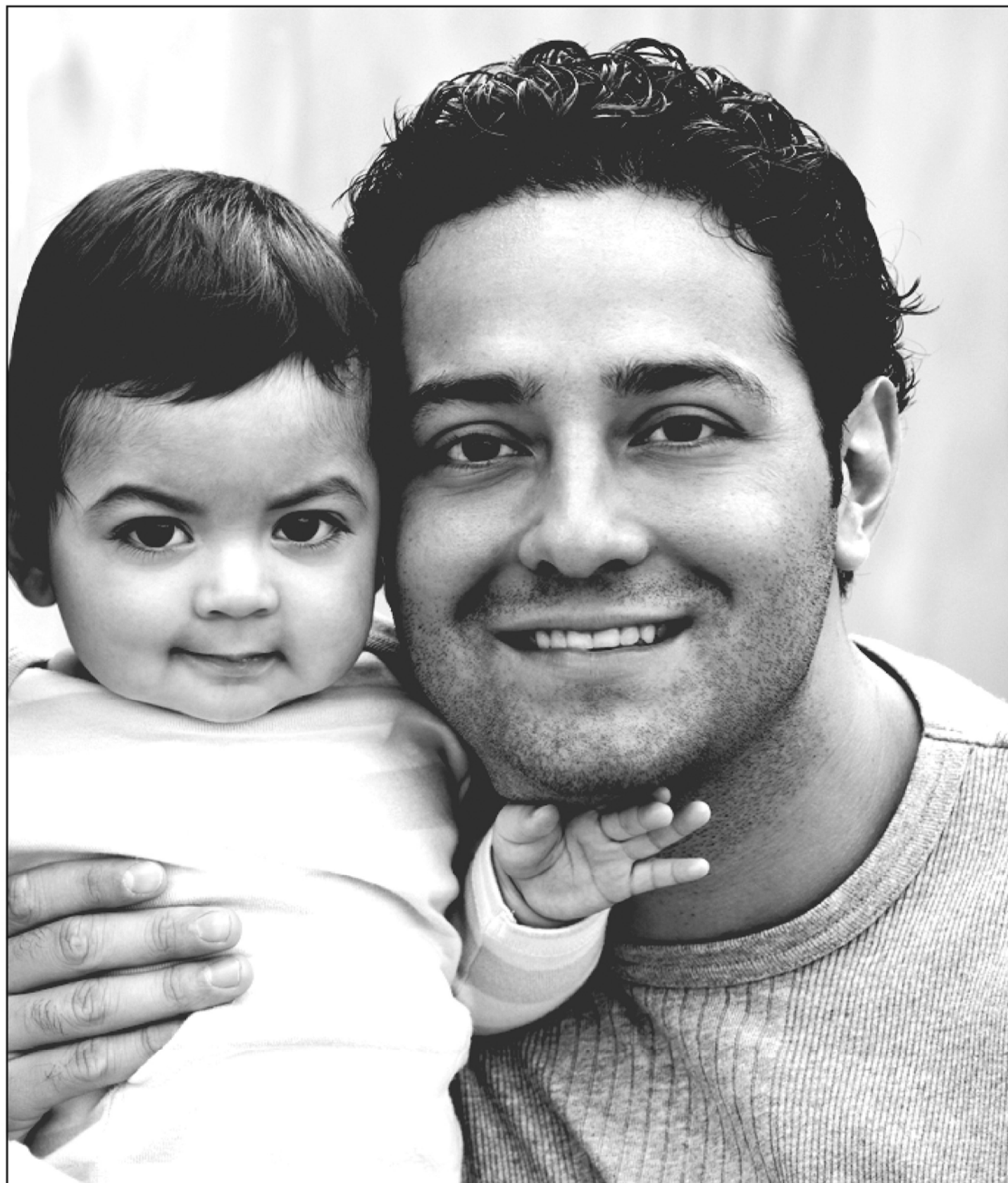
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Perspective from page 23

was in her early 20's and as a result for approximately 30 years refused to leave the apartment she shared with her mother and her brother. There is no question that she was genetically and environmentally susceptible to having significant mental health illness. When her mother died, she faced the reality that if she didn't start to function independently she would have no money, couldn't keep the apartment, and would likely become part of the horrific mental health system that she experienced during her brother's multiple institutionalizations. Today she works in the health field, is independent and travels on public transportation. While she truly did not leave her apartment for more than 30 years, after her mother's death she regained the strength and courage needed to get help and make a life for herself and live in the world amongst people.

I am several years older than Sharon and have strong and vivid memories of this family's tortured life. I remember my cousin, Aaron, in early childhood having uncontrollable tantrums and throwing his shoes out the window of the apartment or down the toilet. When he attended school, I got nightly phone calls and was asked to "help" him with his homework which really meant giving my aunt the answers to the homework questions. I remember my cousin's terrifying behavior when he, his mother, and sister visited my home many times for overnight visits and my normally non-violent father going after him with a belt to "teach him a lesson." Aaron often bullied his mother, but my father could not tolerate this behavior when it occurred in our home and was directed at my mother. Through the years

there were also weekend visits to my aunt, uncle and cousins, but the visits were rarely pleasant.

Aaron and Sharon's mother was my mother's sister and while there had been strong family ties and support in the early years of the family, for many reasons there was little personal contact with them after Aaron's hospitalizations. When I received a phone call that my aunt had died, I felt responsible and truly concerned about my cousin, Sharon. Through the many years of the family estrangement I suspected that my cousin was a recluse rather than believe the "stories" my aunt told about her just being too busy to talk on the phone or being at work. The story of her very sad life and the remarkable path to her recovery is being written about in a book that will hopefully inspire others.

From Sharon - Aaron's Sister

My brother's illness, schizophrenia, deeply affected my family and disrupted our lives in a most profound way. It contributed to my struggle with depression and agoraphobia, because I could not cope with such a complex illness that began when I was a young teenager. It peaked with a violent confrontation with my mother and me one school day morning when I was fifteen. I awoke to loud noises. My brother was screaming at my mother fearing that she was a CIA agent and out to get him. My mother was attacked with an appliance and I was knocked against the wall having been thrown by my hair several times. My brother ran out into the street in his pajamas and he was apprehended by the police and brought to a hospital.

My brother was difficult throughout my childhood, but this was something very

different from anything before. This was the first "outbreak" of such intensity that left my mother and I traumatized for a long time. This happened when my brother was 17, although there were other incidents for many years that made our lives so difficult.

My life began to change starting at the tender age of eight when I experienced the loss of my grandmother and shortly thereafter the loss of my uncle from leukemia. It was all hard to process as was the illness of my Dad's sudden depression, and at times mania. This culminated in my father's suicide when my brother was 12 and I was 11. To protect us we were never told about the true cause of his death and were told he had a heart attack.

After experiencing the deaths of loved ones, I buried my pain that I could not possibly deal with. My mother felt guilty because my brother was born with the umbilical cord wrapped around his neck and she thought that this contributed to his illness. My mother reacted differently than I did to my brother's illness. She became more caustic and I became more withdrawn after having been an outgoing person.

As a child I remember my brother was either harassing my friends verbally or he was withdrawn. My mother sought psychiatric treatment for him at an early age, but we both knew that doctors had not helped my father. It seems to me that doctors were always good at giving advice, but had not experienced the reality of living our lives. Their advice never helped my father or my brother. My brother was seen by private psychiatrists, hospitalized in private institutions for short periods of time, and then put in a state psychiatric hospital for much longer. His illness was very difficult to treat and the right medication was never found. This was in the late 1960's and the

pain and anxiety due to his illness was never ending. After high school I did not get a job, go to college, or have friends. For many years I thought that my job was to try to bring some happiness to my mother. She bought me a car and I would drive her to visit my brother in the hospital, or many times we'd go on long rides without a destination—just to get away.

Years ago mental illness was not discussed openly as it is today and the medications available had terrible side effects that I saw with my brother. My brother died at the age of 36 after years of hospitalization that took its toll on his physical health and did not improve his mental health problems. I retreated within myself and isolated myself for many, many years. When my mother tried to coax me to go out of the apartment, I told her that I would commit suicide if she forced me.

Depression, for those who do not understand it, is the most painful and self-loathing illness imaginable. I never had faith in the mental health system and refused to see any kind of doctor or seek assistance during those many years indoors. After the death of my mother I had to rebuild my life and learn to take care of myself. I finally sought psychological treatment. Today I am independent and work in the health care field and lead a healthy life. Medication has improved my life greatly as has therapy and the love and support of extended family. I will be eternally grateful for their nonjudgmental support and soothing words.

I finally began a new life.

**Author's Note: The names of the brother and sister have been changed at the request of the sister. All information is true and accurate based on my recollections and those of the sister.*

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Second Chance from page 16

provider and day treatment settings to provide a more seamless continuum of care. The Second Chance Program is an important first step in returning long-stay hospital patients to the community, but much work still needs to be done.

Adam J. Savitz, MD, PhD, is Assistant Professor of Psychiatry at the Weill Medical College of Cornell University. For further information on the Second Chance Program, please contact Andrew Bloch, MSW, Program Coordinator at abloch@nyp.org.



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Pathway to Recovery from page 8

schizophrenia. Twenty-one of the thirty recommendations related to medication practices; seven to other psychosocial rehabilitation services, including the provision of skills training to address the deficits in persons with schizophrenia, creating opportunities for positive family involvement in treatment and support, providing vocational services including supported employment programs for those who express interest and the appropriate use of intensive case management and ACT Programs. These recommended practices and other evidence-based practices that have emerged over the last decade now form the core of services at The Bridge.

Borrowing from the world of substance abuse, recovery has also emerged as a core concept in the last decade. The articulate and inspiring Patricia Deegan defines recovery, not as a cure, but as "try [ing] to stay in the driver's seat of my

life. I don't let my illness run me." (*Social Work in Mental Health: Trends and Issues* ed. Uri Aviram. Vol. 25, No. 3, 1997, pp. 11-24). This vision, combined with a new emphasis on peer empowerment and responsibility have had a major impact on reshaping services. Today at The Bridge many programs include peer workers on the staff and the Peer-to-Peer Program offers clients the opportunity to learn and practice the skills of effective advocacy both inside and outside the agency.

In some senses the evolution of the mental health system over the past 55 years has brought The Bridge full circle. Today's clients provide mutual aid and support and, along with staff, they share the knowledge and skills they have developed to empower others. It is an exhilarating experience to witness the fruition of Phillipe Pinel's prescription more than 200 years ago: persons with mental illness claiming the consideration that is their right and being actively engaged in life.

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From the Darkness from page 1

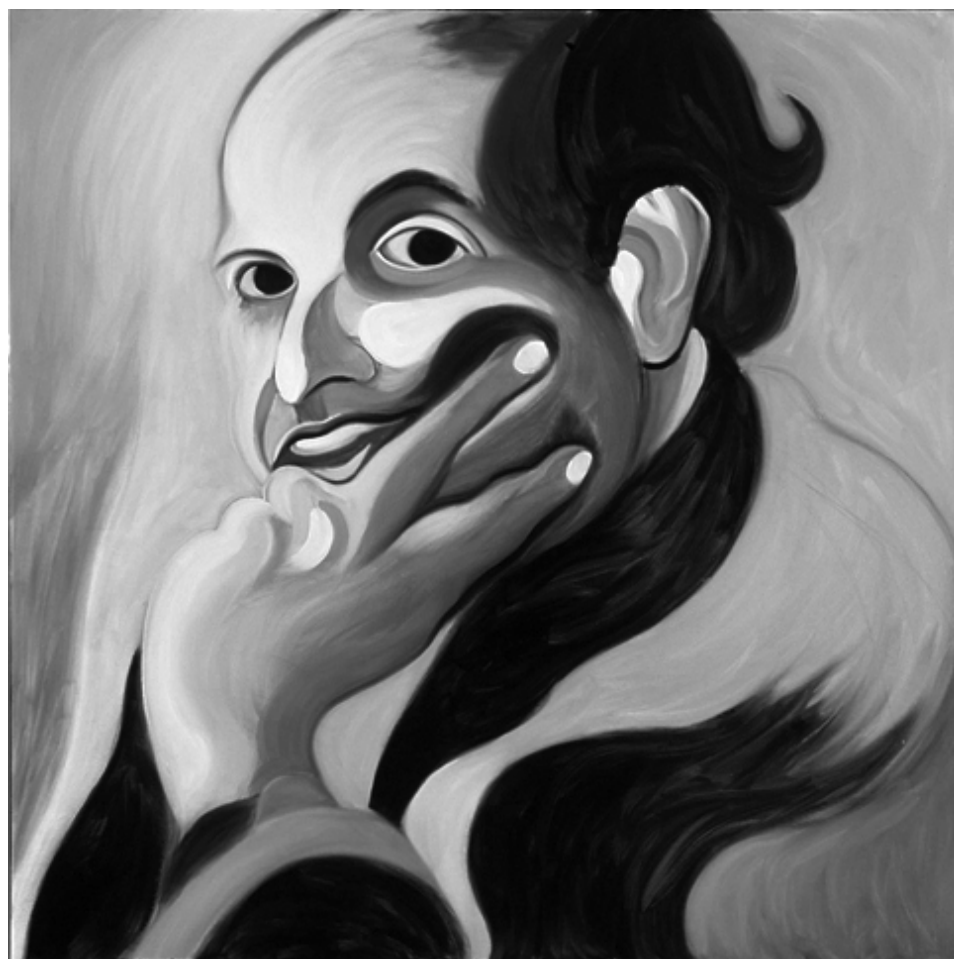
early intervention, even though I was under the care of a psychiatrist. During those early years I decompensated very rapidly because I was not receiving the kind of care I believe I needed at the time. I was treated with many of the older phenothiazine medications that were available back then and was gradually given newer medications as they were developed.

Q: Take us back to your earliest recollections that something just wasn't right with the way you felt as a child.

A: As a child, I grew up in a home where there was very little communication. There was love, but the typical family interactions you might expect to be present in a family were not present in mine. I felt alone at a very early age, but had an almost innate interest and talent in art. My father was an architect, and my mother sculpted when I was very young and I used to model for her. At the age of eight, I built a little art studio for myself in our basement. It was a dark unfinished basement and unfortunately not a very cheerful place. I would go there after school and on weekends. When I wasn't in the basement with my art, I would walk in the woods and felt at home being around nature. I was pretty much a loner, and my art was the only way I could express myself. I was encouraged by my parents and my teachers to pursue my artwork, in spite of the fact that I did poorly in school. I remember having very few friends. When I did make a friend it would not last. Other kids thought I was "snobby" but I just didn't know how to relate to the other kids. I had no social skills and spent my days with my artwork in that dark basement when the other kids were out playing. My childhood was a very dark time for me, and one of the things I remember was being in class one day and writing on my desk "god – please help me."

At around 17 years old, a lot of my dark feelings were coming out in my artwork. I did not want anyone to see what I was painting so I hid my work (even from my family) and kept it in the closet hidden away. I soon went off to college at the Rhode Island School of Design which is a very good school. I was totally unprepared to be out on my own in the world and I started to really fall apart. I became totally withdrawn and lost and falling further into darkness and dark thoughts. I was really hurting and scared. I ended up in the school infirmary and spoke with a counselor on the staff that referred me to my first psychiatrist that I spoke of earlier. The next three years I really took a nose dive and I was kicked out of school – not because I did anything wrong – but because I was ill. This is something that I hope would never happen today.

I was so ill and didn't know enough to do anything about it. My parents at the time were going through a divorce which kept me even further from their intervening on my behalf. The entire family became fragmented, and I lost touch with my father who, because of the divorce, totally dropped out of all family contact. I have only just reconnected with him last year after a 35 year absence. I later learned that he eventually suffered from a severe form of PTSD emanating from his



"Sam" 2003 36" x 36" By Susan Weinreich

past service in World War II. I also learned that schizophrenia had been present on my father's side of the family which was hidden from me, and he had a lot of negative feelings about that as it related to the difficulties I was going through.

During college, I had become so ill that I had to be hospitalized three times (once committed). I didn't tell my family because I didn't want them to know what was going on and because I had so much self loathing, fear, and paranoia.

Q: Was there a pivotal moment during all this that was a turning point for you at this time?

A: Yes. None of the treatments and hospitalizations I received during my time in Rhode Island was really helping me. It wasn't until my psychiatrist who was treating me called my mother saying that he wanted to hospitalize me at McLean Hospital in Massachusetts for three years and needed to find out what type of insurance the family had. My mother got in her car, drove up to Providence, threw me into the car and drove me back home to Connecticut. All I had was the shirt on my back which had cigarette burns and dirt all over it, my jeans I was wearing which I had painted all over it, and all my art supplies which she tossed into the trunk of her car.

This was upsetting to me because even though my doctor wasn't helping me get well, he was my only lifeline at the time. She tore me away from him and brought me to Four Winds Hospital in Katonah, New York, which was closer to my childhood home in Stamford, Connecticut.

Q: What was that like?

A: I remember driving in the car with my mother up the road leading to the main office at Four Winds and thinking that this

is too beautiful and surrounded by nature to be a hospital. I was used to brick buildings with bars on the windows. I remember sitting curled up in the corner of Dr. Samuel Klagsbrun's office, the Executive Medical Director of the hospital. It was early January of 1979 and patients back then had their own private rooms. I remember lying on my bed for months watching the snowy scene outside my window changing to spring and then to summer. There was this one female patient who would come into my room every night, sit by my bed, and read poetry to me. I remember letting her do this, while not letting anyone else get near me at that time. Then, one day, I remember getting up from my bed and hugging her. From then on, she walked me into the day room where they had group therapy and I joined the other patients for the first time. When the spring came, I felt the first lifting of my psychosis in what may have been five to six years. Then there were four or five more hospitalizations at Four Winds after that.

Back to your question about turning points in my illness, I remember when Sam (Dr. Klagsbrun) first told me my diagnosis. It was the first time I had ever heard a label or a name being attached to what was going on with me. You know what? I felt so much more relieved.

It wasn't like "Oh my god a label," "I don't want this on my record," you know? At that point I was like "Whoa – there's a name for this thing." And then in his next breath he told me, "And you can recover from this."

No one had ever said that to me before, or believed that recovery for me was possible. I had this relief that came over me and that was the first turning point. From then on, I continued to fight and struggle with finding the right medications that could help me along the way. I became more open to accepting the need for medications, in spite of the fact I had previ-

ously had a firm belief that I would affect my artistic creativity – which turned out to be absolutely ridiculous. There's that whole theme of creativity and madness and the use of medications – so I struggled with that for some years.

Q: It sounds like Dr. Klagsbrun had a great impact on you and your ability to recover.

A: Yes, he did. I only saw him while I was an inpatient at Four Winds, not in outpatient treatment. As it was, I was an inpatient there for the good part of the year (four to six months at a time), and for several years in a row. Another big turning point for me was during the first year I was under Sam's care at the hospital. He had developed a unique hospice program where people came to Four Winds in the last weeks and months of their life. These hospice patients would join the group therapy with the rest of the patients. You must understand that Sam had just started the hospital itself a year or so before I came, and having such a small number of patients in the hospital back then, was like a family of patients being cared for by the staff.

I remember being exposed to several hospice patients who were dying. It was a very powerful experience for me. Even in my delusional and my psychotic state, I used to sit by the bed of this one woman who was a hospice patient and show her pictures of paintings in an art book. When she died, there were several of us in her room – Sam was there – and we all recited Kaddish (the Jewish prayer for the dead). Even though I was still very psychotic at the time, on some very deep and profound level I realized that this whole experience represented a question for me of whether I wanted to move towards life and living or whether I was progressing towards death. Do I want to live or do I want to die?

Faced with such a reality as death is, even to somebody who is totally psychotic, it touched me on some very deep level.

It was at that moment, that I realized that I wanted to live.

From then on I started to really try to learn, to struggle, to work through everything, and to try to make steps forward instead of backwards.

Editor's note: The hospice program at Four Winds was during its early days and is no longer a program at the hospital.

Q: You speak so fondly of Dr. Klagsbrun as if he was a part of your family. Did there come a time that he said you were better, that you should move on, leave the hospital, and go out into the world and begin to live your life?

A: No (laughter), not really. He actually was amazing in that on some level he actually indirectly encouraged me to have a dependence on the hospital. Not that he directly encouraged this, but I think that because I was so regressed, he played the role of father, mother, and doctor. I was like an infant that needed to be coddled and nurtured. Because of the special way that he treated me, I was able to make a connection with someone, and come out of the imploded and isolated state that I was in. I believe that the nurturing way he treated me enabled me to begin to first

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reach out and try to strive towards life and health and let go of my illness. A part of that was to encourage this special dependence – something that had been absent from my life all the years I was growing up. In other words, the basic building blocks of trust, safety, security, and cognitive independence that all children need to achieve with their parents were never given to me as a child. Of course I am not an expert on treatment, but I believe Sam's treatment approach with me was designed to rebuild this period of my life so that I could become the more completed person I should have achieved during my younger years.

I left Four Winds in 1982 and thought it was going to be my last time there. I was still very sick and very broken but no longer blatantly psychotic. Part of me wanted to help other people with mental illness so I did volunteer work at the hospital with a few young adults who were interested in art. Several years later, I took training and became a mental health worker. During the last year that I was at Four Winds, I started doing some public speaking about my art and my experience with my illness. I decided to put together a slide presentation of my art and I did a dialogue along side of it. I basically talked about my decent into my illness and my recovery to that point. I gave my first presentation in the living room at Four Winds. Everyone from the hospital was there including the kitchen staff, janitorial staff, the patients and all the staff and doctors. They turned the lights down and I gave this hour long presentation. When they turned the lights back on I turned to look at Sam and he was crying.

I couldn't believe that. I was so touched.

From then on I gave more of my slide presentations. Sam took me around to the different hospitals around the NY metropolitan area to give my presentation. I remember getting a call from Dr. Ronald Rieder who was at Columbia University College of Physicians and Surgeons at that time, who invited me to come and talk to his medical residents about my experience with mental illness. It was the 1980's, and since then, I have given a lecture at Columbia every year. I think it was very helpful for them and certainly it was for me.

During the years that followed, I went through three to four clinical depressions each lasting between two to three years in duration. I hooked up with a therapist in New York City who basically brought me through boot camp. I saw her three times a week and since I couldn't afford to pay her I traded my artwork for therapy. She was married to a very famous cellist who was Yo-Yo Ma's teacher. It became twenty years of learning how to eat, walk, sleep, talk differently, change my underwear, take showers, and trying to find some kind of work. I worked as a cashier for eight years part-time. I was still very paranoid, very scared, and very fragile for many years. I think my ego had more holes in it than Swiss cheese and it was just totally shot after all I had gone through. My therapist passed away in 2001 and I went on to work with someone else.

To this day, I am thankful that I had Sam looking over my shoulder to see who was caring for me at any particular time. He had become like a grandfather to me.



“Sunrise Kiss” 2006 48” x 48” By Susan Weinreich

I still check in with him at least once a year. We are now working on a program at the University of Hartford where Sam and I will speak on a panel and I will discuss my artwork. My relationship with Sam, even though it had its boundaries, represented a unique continuity of care for me that he provided. I think that is something people with mental illness do not receive in today's world.

Q: This was a special nurturing relationship. And how did your artwork fit into your recovery?

A: I believe that I developed the ability to problem solve through my painting. I knew all along that I could not spend my life at Four Winds in spite of my feeling a deep and profound connection to the hospital. I knew I would eventually be able to move away from it emotionally and have a life of my own.

To me, a painting is worth a thousand words. When you take someone who becomes withdrawn and isolated as a result of an illness, the ability to connect and communicate with another person becomes obstructed – certainly in schizophrenia. My artwork provided me with a means to communicate what was going on internally in me and was incredibly significant in my recovery process. I did not expect that someone could look at my painting and understand exactly what was going on inside of my head. With an illness such as mine, I was totally cut off from life and everything. My ability to somehow connect with something outside of myself was critical to my survival – whether it was Sam, as it was in the early years, a spiritual life, a rock, a tree or whatever. That connection is where the healing takes place.

Q: Over the course of your illness did you meet other people with schizophrenia? Do you think there are similarities in

people with the same diagnosis or did you think everyone is unique?

A: Everyone's different. I think it's a very unique and individual process – both the deterioration that takes place during a person's illness, and the rebuilding of each person into a more healthy life during the recovery process.

I think that if I had received earlier intervention I would be a lot further on both personally and professionally than I am today. I am still lacking in many areas of my life. Financially, it is very hard for me to take care of myself. I try. I do the best that I can. I lost so many years during which time I could have been gaining a skill or profession to support myself while doing my art. This has been a real tragedy for me. The other thing I lost during my illness was my entire social development. I am 54 years old and have only been able to have an intimate romantic relationship for the first time a couple of years ago and that's been it. I think that's an issue that there just isn't much if any research about. There isn't any data out there about people who are recovering from schizophrenia and about how to start dating much later in life than people usually do (laugh). It has been a frustrating experience for me and I think it's really hard for most people with a severe mental illness.

Q: Do you think that stigma plays any part in that?

A: Absolutely. So much of dating today can be done on the internet. This is great for most people, but horrible for someone like me. That's because I have made such a life for myself that is intertwined with my experiences and advocacy work for mental illness and recovery. As a result of that, my entire history is all over the internet, so anyone that I meet online can simply Google my name and read all

about my struggle with schizophrenia. Before I even get to meet someone in person, it's all over. You know?

Q: Yes, I understand that from my own experience all too well (laugh).

A: Even when I meet someone in person I end up having to explain why I am flying to Montreal to give a lecture, and who am I on a panel with, and why I am doing this and “Oh. You take medication? What's that for?” It's very hard.

Q: If you were to give our readers a final thought about overcoming the hardships of your journey, or their mental illness, the recovery process and if recovery is truly possible, what would you say?

A: I would say that recovery is absolutely possible and absolutely worth-while. The bottom line is that people with mental illness are no different from anyone else. As human beings we all have issues in our lives – whether they're physical illnesses, mental illnesses, disabilities of any kind – we are all struggling to just get through it, develop, grow and face our challenges.

I have met people with schizophrenia. There are people who are doing very, very well, as I am today. Does anyone really know how many people are out there that suffered from a serious mental illness and are now doing OK? That may be a number hard to figure out because most people who have gotten better do not want to talk about the dark days of their lives – it's just too painful.

For me, since my illness was over 35 years in duration, I am not about to deny it, and not have people I love deny that it happened either. It's very much a part of who I am and who I have become.

I believe that people can and do recover from schizophrenia. Everyone is capable of recovering to the most possible level that they are able to reach – and we don't know what that level is.

It's different in every individual. A lot of it, again, has to do with the type of early intervention that people receive. I think that's really crucial. Hopefully people won't have to go through 35-40 years of recovery like I have. With better continuity of care and some of the newer medications that are out there I believe that people do and can recover much faster. I have friends that have. On the other hand, I don't regret the path I have taken. I think that my recovery is a continuous effort and not unlike anyone else's growth throughout this life.

Q: Why do you think people are so frightened of schizophrenia?

A: That's a good question. One of the reason's I think stigma exists and why people are so frightened of this illness is that the components of an illness like schizophrenia are made up of, and lack (in the case of the illness) the same set of emotions, feelings, and human behaviors that each and every one of us take for granted as what makes us “normal” on a daily basis. It's just a question of degree.

I think that when people see someone behaving or talking in a way they do not understand they get scared because they know that they are capable of going there themselves on some level. People who

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when it comes to sarcasm, in which tone of voice is used to indicate that a person means the exact opposite of what is being said. Individuals with schizophrenia show much reduced ability to detect sarcasm, and so are likely to feel that people are being sincere even when they are not.

Projects within the Center are currently investigating why these disturbances develop. For example, neurophysiological ("brain wave") studies are pinpointing the sources of the abnormal activity and determining the exact time at which processing of the auditory information begins to break down. Imaging studies are investigating the structure of auditory cortex, while postmortem studies are probing changes in gene expression in schizophrenia vs. control subjects. In rodents, deficits similar to those seen in individuals with schizophrenia can be produced by administering compounds such as phencyclidine or ketamine that produce schizophrenia-like symptoms by blocking NMDA receptors, suggesting that deficits in NMDA transmission might cause both sensory and cognitive-level disturbances in schizophrenia.

A similar pattern of deficit is observed in the visual system. In the visual system, deficits are observed especially in the part of the brain called the "magnocellular" visual system. This system helps individuals direct their attention to important features of the environment, such as motion, and to get a "quick

and dirty" read of a visual event. As in the auditory system, this deficit affects the ability to recognize emotional expression, which depends upon being able to simultaneously interpret the orientation of face parts such as eyes, cheeks, lips and mouth, as well as to find objects hidden in scenes or even to read paragraphs of words on a page.

Although reading ability was once considered to be unaffected in schizophrenia along with other types of simple sensory processing, in fact patients as a group show severe deficits in reading ability, typically reading on a 3rd-5th grade level. The reading deficits appear to arise during the several years preceding onset of the illness, and so may be an early sign of disease development. Research at NKI is continuing to investigate how and why visual processing breaks down in schizophrenia using brain wave and neuroimaging approaches, as well as parallel studies in animal models. As in the auditory system, these impairments appear to reflect underlying disturbances in the function of NMDA receptor pathways in the brain.

Treatment research at NKI

In addition to investigating basic brain mechanisms, NKI also remains at the forefront of current treatment research. A main goal of these studies is to develop new approaches for treatment of individuals with chronic schizophrenia. A second but perhaps more important goal is to develop approaches to

prevent development of schizophrenia in adolescents and young adults at high risk for developing the disorder. Currently, it appears that there is approximately a 3-year window preceding illness onset for most individuals in which brain changes are already occurring but symptoms have not yet become established. Ongoing studies at NKI are investigating whether intervention during the prodromal period can prevent or delay progression to schizophrenia.

Several of the studies at NKI directly target NMDA receptors using compounds that stimulate NMDA function. In general, these compounds are effective in animal models of schizophrenia, raising hope that they will be effective in the clinic as well. The first of these compounds to become available for investigational use in the US is a natural brain amino acid called D-serine, which stimulates NMDA receptors in brain, and reverses the effects of drugs of abuse such as phencyclidine in animal models. D-Serine was found to be effective in treating persistent symptoms of schizophrenia when added to antipsychotics in two small studies, one conducted in Taiwan and the other in Israel. Studies at NKI are currently investigating the effectiveness of D-serine both in individuals with established schizophrenia and those showing earliest signs of the illness. In addition, studies in rodents and in postmortem human tissue are identifying potential new treatment targets.

In addition, NKI participates in a national research network whose goal is to

identify and evaluate promising new medications. Dr. Javitt recently served as lead investigator of a novel compound named davunetide (AL-108), which is primarily under development for Alzheimer's disease. However, in the recent study, davunetide treatment led to improved activities of daily living in patients with schizophrenia as well, potentially providing an important new direction in schizophrenia treatment. The research network is coordinated by Dr. Steve Marder from UCLA and also includes sites at Harvard, Maryland Psychiatric Research Center, and Columbia/NYSPI.

Finally, not all treatment of schizophrenia relies on medication. Even if underlying neurotransmitter imbalances can be corrected in schizophrenia, rehabilitation strategies need to be developed to reverse the changes in brain structure and function that have built up over years or, in adolescents at risk, to prevent the changes from occurring altogether. Ongoing rehabilitation studies at NKI are identifying ideal approaches for reversing the basic sensory disturbances in schizophrenia and investigating their subsequent effects on brain function. Ultimately, no one approach will solve all of the disturbances associated with schizophrenia. However, by taking a holistic, translational approach the Schizophrenia Research Center at NKI hopes to take advantage of the resources made available to it by both NYS OMH and the NIMH to develop new, improvement strategies for the diagnosis, understanding, and treatment of this important disorder.

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Paxil. As part of a negotiated settlement, GSK posted the results online of all of its studies from December, 2000-forward. Lastly, in 2004, largely in response to the Congressional testimony of Dr. David Graham a whistleblower within the FDA, the Journal of the American Medical Association published a series of papers criticizing certain aspects of the FDA process and suggesting potential reforms. This pressure has resulted in many more drug companies publishing most if not all of their clinical studies regardless of the favorability of the outcome.

New York Law On Experimental Medication

In 1975, in response to the many abuses levied against human subjects of experimental medication trials, the New York State Legislature passed Article 24-A of the Public Health Law to establish guidelines and rules on how experimental medications can be tested on human subjects within the State of New York. At its core, Article 24-A mandates that in order for an individual to be the subject of an experimental trial that individual must provide informed consent. In essence, that the individual fully understands the risks, any potential benefits, and alternatives of the experimental protocol and nevertheless agrees to take part in the clinical trial. The Public Health Law gave the Commissioner of the Department of Health the

exclusive authority to promulgate rules and regulations on how to enact and comply with the mandates of Article 24-A. However, in studies conducted by and fully funded by the Federal government, Article 24-A does not apply, and instead, any applicable Federal regulations would control how the study was to be conducted.

In 1990, the Office of Mental Health (OMH) passed a series of rules regulating the provision of experimental psychotropic medications to patients at OMH licensed facilities. These regulations controlled the provision of experimental medication not only to those who maintained the capacity to provide informed consent, but also to those individuals who were incapacitated thereby leaving them unable to render a reasoned decision about whether or not they wanted to be a part of the study. While safeguards were put in place, the regulations allowed for the human experimentation on a population of individuals who could not, as a result of their mental illness, understand what they were a part of.

Due to the serious concerns raised by these new OMH regulations a series of mental health advocacy groups, including the Mental Hygiene Legal Service, collaborated in challenging the OMH regulations. In the seminal case of *T.D. v. OMH*, the Court struck down the OMH regulations as violative of the New York State and Federal Constitution. The Court reasoned that the Commissioner of OMH lacked any authority under State

Law to issue these regulations as Article 24-A of the Public Health Law gave this exclusive authority to the Commissioner of the Department of Health. Moreover, the Court discussed the more troubling aspect of the OMH regulations, which allowed patients who were so mentally ill that they had no idea what medications they were taking or whether they were safe to take or not.

The Court had particular issue with the fact that pursuant to the regulations, if an individual was being considered for participation in a clinical trial, and that individual's capacity to consent was in question, there was no provision that the individual be notified that his/her capacity was in question. Hence, it was quite possible that an individual may have been a part of a study without having any idea of their own involvement. Moreover, even if the individual was aware that he was adjudged incapacitated there was no provision within the regulations to test the determination of capacity. Lastly, the regulations allowed for testing on individuals even where the drug being tested held no hope for improving the mentally ill individual's condition. Thus, this particular group of patients was truly being taken advantage of; suffering all of the risk with no potential benefit. The Court was particularly troubled by this aspect.

As noted previously, the Court struck down the OMH regulations, reverting the law back to its original position with Article 24-A controlling. Hence, if an individual is to be the subject of a clinical trial

with an experimental drug that individual must provide informed consent, or a duly authorized representative must provide informed consent on behalf of that individual. Those individuals who lack the capacity to make a decision, and have no legal representative to make that decision for them, cannot be forced to participate in clinical human trials of experimental drugs.

Conclusion

Because of the extremely sensitive nature of experimental psychiatric medication it is not surprising that there is so much controversy over the issue. The venture has outstanding abilities to create a great deal of good for the mentally ill community if the promise of more effective and less dangerous medication can be discovered; human clinical trials is the only way this can be achieved. However, at what risk? This dilemma continues both in the FDA approval process and New York's attempts to establish procedures that will allow for the obvious benefits of clinical trials while minimizing the risk to those participating in the study. What does seem clear, however, is that the regulations established by OMH, and struck down in *T.D. v. OMH*, went too far. It is difficult to contemplate a circumstance where a patient who lacks the ability to understand what he is involved in, be involuntarily made to participate in a study involving potentially dangerous experimental medications.

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When does schizophrenia start and who gets it?

Schizophrenia affects men and women equally. It occurs at similar rates in all ethnic groups around the world. Symptoms such as hallucinations and delusions usually start between ages 16 and 30. Men tend to experience symptoms a little earlier than women. Most of the time, people do not get schizophrenia after age 45. Schizophrenia rarely occurs in children, but awareness of childhood-onset schizophrenia is increasing.

It can be difficult to diagnose schizophrenia in teens. This is because the first signs can include a change of friends, a drop in grades, sleep problems, and irritability—behaviors that are common among teens. A combination of factors can predict schizophrenia in up to 80 percent of youth who are at high risk of developing the illness. These factors include isolating oneself and withdrawing from others, an increase in unusual thoughts and suspicions, and a family history of psychosis. In young people who develop the disease, this stage of the disorder is called the “prodromal” period.

Are people with schizophrenia violent?

People with schizophrenia are not usually violent. In fact, most violent crimes are not committed by people with schizophrenia. However, some symptoms are associated with violence, such as delusions of persecution. Substance abuse may also increase the chance a person will

become violent. If a person with schizophrenia becomes violent, the violence is usually directed at family members and tends to take place at home.

The risk of violence among people with schizophrenia is small. But people with the illness attempt suicide much more often than others. About 10 percent (especially young adult males) die by suicide. It is hard to predict which people with schizophrenia are prone to suicide. If you know someone who talks about or attempts suicide, help him or her find professional help right away.

What about substance abuse?

Some people who abuse drugs show symptoms similar to those of schizophrenia. Therefore, people with schizophrenia may be mistaken for people who are affected by drugs. Most researchers do not believe that substance abuse causes schizophrenia. However, people who have schizophrenia are much more likely to have a substance or alcohol abuse problem than the general population.

Substance abuse can make treatment for schizophrenia less effective. Some drugs, like marijuana and stimulants such as amphetamines or cocaine, may make symptoms worse. In fact, research has found increasing evidence of a link between marijuana and schizophrenia symptoms. In addition, people who abuse drugs are less likely to follow their treatment plan.

Schizophrenia and smoking

Addiction to nicotine is the most common form of substance abuse in people with

schizophrenia. They are addicted to nicotine at three times the rate of the general population (75 to 90 percent vs. 25 to 30 percent).

The relationship between smoking and schizophrenia is complex. People with schizophrenia seem to be driven to smoke, and researchers are exploring whether there is a biological basis for this need. In addition to its known health hazards, several studies have found that smoking may make antipsychotic drugs less effective.

Quitting smoking may be very difficult for people with schizophrenia because nicotine withdrawal may cause their psychotic symptoms to get worse for a while. Quitting strategies that include nicotine replacement methods may be easier for patients to handle. Doctors who treat people with schizophrenia should watch their patients' response to antipsychotic medication carefully if the patient decides to start or stop smoking.

What causes schizophrenia?

Experts think schizophrenia is caused by several factors.

Genes and environment. Scientists have long known that schizophrenia runs in families. The illness occurs in 1 percent of the general population, but it occurs in 10 percent of people who have a first-degree relative with the disorder, such as a parent, brother, or sister. People who have second-degree relatives (aunts, uncles, grandparents, or cousins) with the disease also develop schizophrenia more often than the general population. The risk is highest for an identical twin of a person with schizophrenia. He or she has a 40 to 65 percent chance of developing the disorder.

We inherit our genes from both parents. Scientists believe several genes are associated with an increased risk of schizophrenia, but that no gene causes the disease by itself. In fact, recent research has found that people with schizophrenia tend to have higher rates of rare genetic mutations. These genetic differences involve hundreds of different genes and probably disrupt brain development.

Other recent studies suggest that schizophrenia may result in part when a certain gene that is key to making important brain chemicals malfunctions. This problem may affect the part of the brain involved in developing higher functioning skills. Research into this gene is ongoing, so it is not yet possible to use the genetic information to predict who will develop the disease.

Despite this, tests that scan a person's genes can be bought without a prescription or a health professional's advice. Ads for the tests suggest that with a saliva sample, a company can determine if a client is at risk for developing specific diseases, including schizophrenia. However, scientists don't yet know all of the gene variations that contribute to schizophrenia. Those that are known raise the risk only by very small amounts. Therefore, these “genome scans” are unlikely to provide a complete picture of a person's risk for developing a mental disorder like schizophrenia.

In addition, it probably takes more than genes to cause the disorder. Scientists think interactions between genes and the environment are necessary for schizophrenia

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to develop. Many environmental factors may be involved, such as exposure to viruses or malnutrition before birth, problems during birth, and other not yet known psychosocial factors.

Different brain chemistry and structure. Scientists think that an imbalance in the complex, interrelated chemical reactions of the brain involving the neurotransmitters dopamine and glutamate, and possibly others, plays a role in schizophrenia. Neurotransmitters are substances that allow brain cells to communicate with each other. Scientists are learning more about brain chemistry and its link to schizophrenia.

Also, in small ways the brains of people with schizophrenia look different than those of healthy people. For example, fluid-filled cavities at the center of the brain, called ventricles, are larger in some people with schizophrenia. The brains of people with the illness also tend to have less gray matter, and some areas of the brain may have less or more activity.

Studies of brain tissue after death also have revealed differences in the brains of people with schizophrenia. Scientists found small changes in the distribution or characteristics of brain cells that likely occurred before birth. Some experts think problems during brain development before birth may lead to faulty connections. The problem may not show up in a person until puberty. The brain undergoes major changes during puberty, and these changes could trigger psychotic symptoms. Scientists have learned a lot about schizophrenia, but more research is needed to help explain how it develops.

How is schizophrenia treated?

Because the causes of schizophrenia are still unknown, treatments focus on eliminating the symptoms of the disease. Treatments include antipsychotic medications and various psychosocial treatments.

Antipsychotic medications

Antipsychotic medications have been available since the mid-1950's. The older types are called conventional or "typical" antipsychotics. Some of the more commonly used typical medications include:

- Chlorpromazine (Thorazine)
- Haloperidol (Haldol)
- Perphenazine (Etrafon, Trilafon)
- Fluphenazine (Prolixin).

In the 1990's, new antipsychotic medications were developed. These new medications are called second generation, or "atypical" antipsychotics.

One of these medications, clozapine (Clozaril) is an effective medication that treats psychotic symptoms, hallucinations, and breaks with reality. But clozapine can sometimes cause a serious problem called agranulocytosis, which is a loss of the white blood cells that help a person fight infection. People who take clozapine must get their white blood cell counts checked every week or two. This problem and the cost of blood tests make treatment with clozapine difficult for many people. But clozapine is potentially helpful for people

who do not respond to other antipsychotic medications.

Other atypical antipsychotics were also developed. None cause agranulocytosis. Examples include:

- Risperidone (Risperdal)
- Olanzapine (Zyprexa)
- Quetiapine (Seroquel)
- Ziprasidone (Geodon)
- Aripiprazole (Abilify)
- Paliperidone (Invega).

What are the side effects?

Some people have side effects when they start taking these medications. Most side effects go away after a few days and often can be managed successfully. People who are taking antipsychotics should not drive until they adjust to their new medication. Side effects of many antipsychotics include:

- Drowsiness
- Dizziness when changing positions
- Blurred vision
- Rapid heartbeat
- Sensitivity to the sun
- Skin rashes
- Menstrual problems for women.

Atypical antipsychotic medications can cause major weight gain and changes in a person's metabolism. This may increase a person's risk of getting diabetes and high cholesterol. A person's weight, glucose levels, and lipid levels should be monitored regularly by a doctor while taking an atypical antipsychotic medication.

Typical antipsychotic medications can cause side effects related to physical movement, such as:

- Rigidity
- Persistent muscle spasms
- Tremors
- Restlessness.

Long-term use of typical antipsychotic medications may lead to a condition called tardive dyskinesia (TD). TD causes muscle movements a person can't control. The movements commonly happen around the mouth. TD can range from mild to severe, and in some people the problem cannot be cured. Sometimes people with TD recover partially or fully after they stop taking the medication.

TD happens to fewer people who take the atypical antipsychotics, but some people may still get TD. People who think that they might have TD should check with their doctor before stopping their medication.

How are antipsychotics taken and how do people respond to them?

Antipsychotics are usually in pill or liquid form. Some anti-psychotics are

shots that are given once or twice a month.

Symptoms of schizophrenia, such as feeling agitated and having hallucinations, usually go away within days. Symptoms like delusions usually go away within a few weeks. After about six weeks, many people will see a lot of improvement.

However, people respond in different ways to antipsychotic medications, and no one can tell beforehand how a person will respond. Sometimes a person needs to try several medications before finding the right one. Doctors and patients can work together to find the best medication or medication combination, as well as the right dose.

Some people may have a relapse-their symptoms come back or get worse. Usually, relapses happen when people stop taking their medication, or when they only take it sometimes. Some people stop taking the medication because they feel better or they may feel they don't need it anymore. But no one should stop taking an antipsychotic medication without talking to his or her doctor. When a doctor says it is okay to stop taking a medication, it should be gradually tapered off, never stopped suddenly.

How do antipsychotics interact with other medications?

Antipsychotics can produce unpleasant or dangerous side effects when taken with certain medications. For this reason, all doctors treating a patient need to be aware of all the medications that person is taking. Doctors need to know about prescription and over-the-counter medicine, vitamins, minerals, and herbal supplements. People also need to discuss any alcohol or other drug use with their doctor.

To find out more about how antipsychotics work, the National Institute of Mental Health (NIMH) funded a study called CATIE (Clinical Antipsychotic Trials of Intervention Effectiveness). This study compared the effectiveness and side effects of five antipsychotics used to treat people with schizophrenia. In general, the study found that the older typical antipsychotic perphenazine (Trilafon) worked as well as the newer, atypical medications. But because people respond differently to different medications, it is important that treatments be designed carefully for each person. More information about CATIE is on the NIMH website.

Psychosocial treatments

Psychosocial treatments can help people with schizophrenia who are already stabilized on antipsychotic medication. Psychosocial treatments help these patients deal with the everyday challenges of the illness, such as difficulty with communication, self-care, work, and forming and keeping relationships. Learning and using coping mechanisms to address these problems allow people with schizophrenia to socialize and attend school and work.

Patients who receive regular psychosocial treatment also are more likely to keep taking their medication, and they are less likely to have relapses or be hospitalized. A therapist can help patients better understand and adjust to living with schizophrenia. The therapist can provide education about the disorder, common symptoms or problems patients may experience, and the importance of staying on medications.

For more information on psychosocial treatments, see the psychotherapies section on the NIMH website.

Illness management skills. People with schizophrenia can take an active role in managing their own illness. Once patients learn basic facts about schizophrenia and its treatment, they can make informed decisions about their care. If they know how to watch for the early warning signs of relapse and make a plan to respond, patients can learn to prevent relapses. Patients can also use coping skills to deal with persistent symptoms.

Integrated treatment for co-occurring substance abuse. Substance abuse is the most common co-occurring disorder in people with schizophrenia. But ordinary substance abuse treatment programs usually do not address this population's special needs. When schizophrenia treatment programs and drug treatment programs are used together, patients get better results.

Rehabilitation. Rehabilitation emphasizes social and vocational training to help people with schizophrenia function better in their communities. Because schizophrenia usually develops in people during the critical career-forming years of life (ages 18 to 35), and because the disease makes normal thinking and functioning difficult, most patients do not receive training in the skills needed for a job.

Rehabilitation programs can include job counseling and training, money management counseling, help in learning to use public transportation, and opportunities to practice communication skills. Rehabilitation programs work well when they include both job training and specific therapy designed to improve cognitive or thinking skills. Programs like this help patients hold jobs, remember important details, and improve their functioning.

Family education. People with schizophrenia are often discharged from the hospital into the care of their families. So it is important that family members know as much as possible about the disease. With the help of a therapist, family members can learn coping strategies and problem-solving skills. In this way the family can help make sure their loved one sticks with treatment and stays on his or her medication. Families should learn where to find outpatient and family services.

Cognitive behavioral therapy. Cognitive behavioral therapy (CBT) is a type of psychotherapy that focuses on thinking and behavior. CBT helps patients with symptoms that do not go away even when they take medication. The therapist teaches people with schizophrenia how to test the reality of their thoughts and perceptions, how to "not listen" to their voices, and how to manage their symptoms overall. CBT can help reduce the severity of symptoms and reduce the risk of relapse.

Self-help groups. Self-help groups for people with schizophrenia and their families are becoming more common. Professional therapists usually are not involved, but group members support and comfort each other. People in self-help groups know that others are facing the same problems, which can help everyone feel less isolated. The networking that takes place in self-help groups can also prompt families to work together to advocate for research and more hospital and community

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From the Darkness from page 33

look at me and how I was may think "Wow, if she can be in that condition, maybe I could also become that way too."

Q: I understand. My experience with depression taught me that we all walk a very thin line, and at anytime, any one of

us can fall off that thin line of normalcy onto the side of an illness, mental or physical, no matter who we are or at what station in life we might be at.

A: Yes. And the treatment professionals and service providers who helped me the most were the people that were in touch with that idea. I am grateful to all of

those who have helped me along the way. Today, I am also grateful that I can share my story as a way of inspiring others who might be going through a difficult time in their life.

Susan Weinreich is currently working on a documentary about her recovery, titled "Changing Minds", with Ne-

braska film maker Gary Hochman. You can view Susan's artwork on her website at www.susanweinreich.com. Her art studio is located at 1006 Brown Street - Studio 208, Peekskill, New York, 10566. To inquire about purchasing her artwork or to discuss possible speaking engagements, you can email her at weinreich55@aol.com.

The Internet from page 24

above, always be judicious in your use of the Internet as a source of definitive information concerning mental health issues.

- By exercising appropriate caution, the knowledge you get from the web can help you become more "mental health literate," help you learn what questions to ask, and enable you to better communicate with professionals

Be cautious about sharing private information over the Internet; you can't be sure that information you divulge will remain private

- Most times, people with schizophrenia or their families are seeking information from the Internet. But there may be some instances where you will decide to voluntarily offer information on-line. Before you fill out any forms or reveal any information about yourself or your family,

make sure you review the site's "privacy policy"

- When you post messages in chat rooms or on bulletin boards, consider using a pseudonym.

Librarians, either at your local library or at a university health sciences library, can also be invaluable in pointing you in the right direction and helping you perform searches for specific information. If you're not sure about the credibility of something you are reading or its appropriateness to your condition, don't be afraid to discuss it with your doctor or another treatment professional. Mental health literacy is everyone's responsibility, and good professionals understand that patients and families need to help direct their own healthcare and be their own advocates.

Drs. Levine are the co-authors of Schizophrenia for Dummies (Wiley). Their book also provides a list of credible web sites for people interested in schizophrenia.

Point of View from page 12

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Comprehensive Review from page 36

treatment programs. Also, groups may be able to draw public attention to the discrimination many people with mental illnesses face.

How can you help a person with schizophrenia?

People with schizophrenia can get help from professional case managers and caregivers at residential or day programs. However, family members usually are a patient's primary caregivers.

People with schizophrenia often resist treatment. They may not think they need help because they believe their delusions or hallucinations are real. In these cases, family and friends may need to take action to keep their loved one safe. Laws vary from state to state, and it can be difficult to force a person with a mental disorder into treatment or hospitalization. But when a person becomes dangerous to himself or herself, or to others, family members or friends

may have to call the police to take their loved one to the hospital.

Treatment at the hospital. In the emergency room, a mental health professional will assess the patient and determine whether a voluntary or involuntary admission is needed. For a person to be admitted involuntarily, the law states that the professional must witness psychotic behavior and hear the person voice delusional thoughts. Family and friends can provide needed information to help a mental health professional make a decision.

After a loved one leaves the hospital. Family and friends can help their loved ones get treatment and take their medication once they go home. If patients stop taking their medication or stop going to follow-up appointments, their symptoms likely will return. Sometimes symptoms become severe for people who stop their medication and treatment. This is dangerous, since they may become unable to care for themselves. Some people end up on the street or in jail, where they rarely receive the kind of help they need.

Family and friends can also help patients set realistic goals and learn to function in the world. Each step toward these goals should be small and taken one at a time. The patient will need support during this time. When people with a mental illness are pressured and criticized, they usually do not get well. Often, their symptoms may get worse. Telling them when they are doing something right is the best way to help them move forward.

It can be difficult to know how to respond to someone with schizophrenia who makes strange or clearly false statements. Remember that these beliefs or hallucinations seem very real to the person. It is not helpful to say they are wrong or imaginary. But going along with the delusions is not helpful, either. Instead, calmly say that you see things differently. Tell them that you acknowledge that everyone has the right to see things his or her own way. In addition, it is important to understand that schizophrenia is a biological illness. Being respectful, supportive, and kind without

tolerating dangerous or inappropriate behavior is the best way to approach people with this disorder.

What is the outlook for the future?

The outlook for people with schizophrenia continues to improve. Although there is no cure, treatments that work well are available. Many people with schizophrenia improve enough to lead independent, satisfying lives.

Continued research and understanding in genetics, neuroscience, and behavioral science will help scientists and health professionals understand the causes of the disorder and how it may be predicted and prevented. This work will help experts develop better treatments to help people with schizophrenia achieve their full potential. Families and individuals who are living with schizophrenia are encouraged to participate in clinical research. For up-to-date information about the latest NIMH-funded research in schizophrenia, see the NIMH Website: www.nimh.nih.gov.

Myths from page 22

threshold amount if that person has: Impairment Related Work Expenses; or Blind Work Expense; or A Plan to Achieve Self Support; or a Personal attendant whose fees are publicly funded; or Medical expenses above the average State amount.

Section 1619b also provides for a beneficiary to resume SSI payments should they ever relapse into their disability again without reapplying for the bene-

fit. In other words, if a person should start work and lose their Medicaid because they made too much money, but not over their states threshold, (in New York for 2009 the threshold is \$43,421) they can ask SSA to implement 1619b. Should that same person have a relapse of their disability, say 4 years down the road, provided they are still receiving the 1619b benefit, they can simply notify their local SSA field office and say "I am no longer working due to my disability" and their benefit will automatically start the next

month and they will receive a check without reapplying. If a person living in New York is making over the \$43,421 threshold but under \$55,000 annually, they are eligible for the Medicaid Buy in offered through the NYS Department of Health. For more information on the Medicaid Buy In for Working People with Disabilities or MBI WPD, visit the NYS Department of Health's website at www.health.state.ny.us.

So there really is no reason not to try and go back to work. The outcome is safer

than most think and depending on the ambition of the person on benefits, success could be within reach where fear and failure seemed to dominate over ones desires and dreams.

To learn more about what is available for Social Security recipients, visit www.ssa.gov or attend one of the many trainings throughout NY given by the NYS OMH Bureau of Consumer Affairs. For a schedule of trainings or to be put on an e-mail list, contact Tom O'Clair at coratpo@omh.state.ny.us



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The Future from page 9

(phase II studies), then to gain FDA approval (phase III studies) and then in the post-marketing period to seek additional indications or in trials against competitors (phase IV studies). Due to concerns that there was not a source of objective and scientifically rigorous data about the comparative effectiveness of antipsychotic drugs the NIMH sponsored the CATIE Study (Clinical Antipsychotic Trials of Intervention Effectiveness) the results of which deflated many of the exaggerated claims about the superiority of the second generation antipsychotic drugs. In the wake of studies like CATIE, the federal government has mandated that a program in comparative effectiveness research be implemented and has allocated funds for this purpose. The exact means by which this research will be enacted and through what agencies it will be supported are not yet known but it will certainly come to pass within the next year. This will provide a means by which systematic evaluation of marketed medications can be carried out and made available to clinicians. This information will then guide the selection of treatments and their usage and combination. One example of the way that this type of information can be used is reflected in the form of a clinical care pathway called SHAPEMEDS that has been developed by the NYS-OMH and provides guidance to clinicians on medication selection, dose, efficacy, side effects, medical comorbidity, adherence, and cost based on existing data.

With all the challenges that we face in providing mental health care to a diverse array of patients suffering from the major mental disorders, it is easy to see the glass as half empty rather than half full. However, I have no doubt that we have come a long way in the evolution of mental health care and already overcome the most difficult challenges. I firmly believe that the future is bright and will provide for a greater knowledge base about mental illness, capacity for their treatment and improving the quality of mental health care for generations to come.

Jeffrey A. Lieberman, MD, is a physician and scientist who has spent his career of over 25 years caring for patients and studying the nature and treatment of mental illness. Dr. Lieberman is currently is the Lawrence E. Kolb Professor and Chairman of Psychiatry at the Columbia University College of Physicians and Surgeons and Director of the New York State Psychiatric Institute. He also holds the Lieber Chair and Directs the Lieber Center for Schizophrenia Research in the Department of Psychiatry at Columbia and serves as the Psychiatrist in Chief of New York Presbyterian Hospital- Columbia University Medical Center. Dr. Lieberman received his medical degree from the George Washington School of Medicine in 1975. Following his postgraduate training in psychiatry at St. Vincent's Hospital and Medical Center of New York Medical College, he was on the faculties of the Mount Sinai School of Medicine and Albert Einstein College of Medicine, and

served as Director of Research at the Hillside Hospital of Long Island Jewish Medical Center. Prior to moving to Columbia University he was Vice Chairman for Research and Scientific Affairs in the Department of Psychiatry and Director of the Mental Health and Neuroscience Clinical Research Center at the University of North Carolina at Chapel Hill School of Medicine.

Dr. Lieberman's research has focused on the neurobiology, pharmacology and treatment of schizophrenia and related psychotic disorders. In this context, his work has advanced our understanding of the natural history and pathophysiology of schizophrenia and the pharmacology and clinical effectiveness of antipsychotic drugs. In terms of the latter, he served as Principal Investigator of the Clinical Antipsychotic Trials of Intervention Effectiveness Research Program (CATIE), sponsored by the NIMH. His research has been supported by grants from the National Institutes of Health and the NARSAD, Stanley, and Mental Illness Foundations. His work has been reported in more than 400 articles in the scientific literature and he has edited or co-edited eight books, including the textbook *Psychiatry*, currently in its second edition; *Textbook of Schizophrenia*, *Comprehensive Care of Schizophrenia*; *Psychiatric Drugs*; and *Ethics in Psychiatric Research: A Resource Manual on Human Subjects Protection*. He also serves, or has served, as Associate Editor of the *American Journal of Psychiatry*, *Biological Psychiatry*, *Neuropsychopharmacology*, *Acta Psychiatrica Scandinavica*, *Schizophrenia Research*,

Neuroimage, *International Journal of Neuropsychopharmacology*, and the *Schizophrenia Bulletin*.

Dr. Lieberman is a member of the National Academy of Sciences Institute of Medicine and recipient of the Lieber Prize for Schizophrenia Research from NARSAD, the Adolph Meyer Award from the American Psychiatric Association, the Stanley R. Dean Award for Schizophrenia Research from the American College of Psychiatry, the APA Research Award, the APA Kempf Award for Research in Psychobiology, the APA Gralnick Award for Schizophrenia Research, the Ziskind-Somerfeld Award of the Society of Biological Psychiatry, the Ernest Strecker Award of the University of Pennsylvania, the Lilly Neuroscience Award from the Collegium Internationale Neuro-Psychopharmacologicum for Clinical Research and the Exemplary Psychiatrist Award from the National Alliance of the Mentally Ill. He is or has been a member of the advisory committee for Neuropharmacologic and Psychopharmacologic Drugs of the Food and Drug Administration, the Planning Board for the Surgeon General's Report on Mental Health, the Committee on Research on Psychiatric Treatments of the American Psychiatric Association (APA), the APA Work Group for the Development of Schizophrenia Treatment Guidelines, the National Advisory Mental Health Council of the National Institute of Mental Health and currently chairs the APA Council of Research and Quality Assessment.

He resides with his wife and two sons in New York City.

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