

Data Trends

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From the Research and Training Center for Children's Mental Health,
Tampa, Florida...

This News brief alerts you to the final report of the NAMI Policy Research Institute Task Force on Serious Mental Illness Research, *Roadmap to recovery and cure*. Incorporating insights from experts in mental health research, consumers, families, and stakeholders, this 40 page document provides recommendations for identifying ways in which serious mental illness can be rapidly improved. Recommendations made by the task force include:

- 1) Significant increases in funding of NIMH basic, clinical, and health services research focused on serious mental illnesses
- 2) Increased application of the NIH's Roadmap to medical research initiative to serious mental illnesses
- 3) The continuation and expansion of clinical trial networks focused on serious mental illnesses
- 4) Coordination of serious mental illness research, dissemination, and service system policy efforts by the federal government
- 5) Increased training and support of researchers and mental health care providers

The report is available by clicking here (actual link follows).
http://www.nami.org/Content/NavigationMenu/Inform_Yourself/About_Public_Policy/Policy_Research_Institute/NAMI_Research_Task_Force_Report-03-2004.pdf

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**POLICY RESEARCH
INSTITUTE**

Roadmap to Recovery & Cure

Final Report of the NAMI Policy
Research Institute Task Force on
Serious Mental Illness Research

February 2004



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Roadmap to Recovery and Cure
 Report of the NAMI Policy Research Institute Task Force on
 Serious Mental Illness Research

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Acknowledgements

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Many members of the Research Task Force gave enlightening presentations on the opportunities for increased research of serious mental illness during our meeting that helped to frame the work of the Task Force. We would like to especially acknowledge the contributions of Edward Scolnick, M.D., Jeffrey Lieberman, M.D., Kimberly Hoagwood, Ph.D., Bob Drake, M.D., and Charles Reynolds, III, M.D.

Finally, we would like to recognize the work of several of NAMI's staff members who assisted in the development of this report, especially Michael Fitzpatrick, M.S.W., Joel Miller, M.S.Ed., and Elise Resnick. We are also appreciative of the assistance of our interns, Ronald Crouch and Tina Renneisen in preparing background materials for the Research Task Force meeting.

NAMI Policy Research Institute

The NAMI Policy Research Institute (NPRI) is one of the nation's foremost consumer- and family-oriented policy groups dedicated to addressing mental illness issues across the life span. The Institute's mission is to drive national, state, and local debates on reforms and investments in the nation's mental illness delivery and financing system. As part of its mission, the Institute provides

technical assistance to NAMI state organizations and local affiliates on pivotal issues such as Medicaid financing, access to medications, and children's delivery issues. The Institute brings together policy-makers, advocates, and scientists through various forums, including special task forces, to develop solutions and expand support for science-based, recession-proof treatment and recovery systems.

Executive Summary

NAMI's Policy Research Institute convened a Task Force on Research, including experts in mental illness research along with consumer, family, and provider stakeholders. Their charge was to identify ways in which serious mental illness treatment could be rapidly improved. The Task Force concluded that dramatic improvements in patients' lives could be realized in the next ten years if research was expanded and the treatment system reformed and brought into closer alignment with research.

A significant rationale for the Task Force's conclusions was advances in genetic, molecular, and neuroscience research, which have already produced significant scientific breakthroughs in psychiatry in recent years. Specific genes involved in mental disorders are being identified and how these genes interact with environmental factors to affect the brain and behavior and produce illness is also being studied. These advances will vastly improve treatments and diagnostic approaches for serious mental illnesses.

Continuing and expanding these basic research advances and translating them into treatment development, as well as improving the implementation of existing effective treatments, were viewed by the Task Force as a public health priority. These brain illnesses pose an enormous burden on individuals as well as on society. Achieving these goals requires increased investment in serious mental illness research as well as the implementation of research and treatment approaches akin to other areas of medicine. The Task Force concluded that: Serious mental illness research has been underfunded, compared to other chronic, disabling illnesses, and is insufficiently prioritized at the National Institute of Mental Health (NIMH). The psychiatric research

enterprise has only begun to enter into the modern era of biomedicine, which is characterized by a strong base of interdisciplinary basic research, large clinical trial networks and population studies, and clinical and health services research intimately tied to the service delivery system, all elements of the National Institutes of Health (NIH) *Roadmap to Medical Research* Initiative. The treatment system itself is in a shambles, failing to deliver scientifically-based interventions that promote optimal consumer recovery, due to system fragmentation and poorly trained and poorly reimbursed providers.

In order to expedite improved treatment and recovery from serious mental illnesses, the Task Force recommends:

- significant increases in funding of NIMH basic, clinical, and health services research focused on serious mental illnesses;
- increased application of the NIH's *Roadmap to Medical Research* Initiative to serious mental illnesses;
- the continuation and expansion of clinical trial networks focused on serious mental illnesses;
- coordination of serious mental illness research, dissemination, and service system policy efforts by the federal government;
- increased training and support of researchers and mental health care providers.

Only with these actions will the goal of vastly improved treatments, with fewer side-effects, be rapidly achieved for people with serious mental illnesses, giving these individuals hope for improved lives in the community and reducing the burden of mental illness on society at large.

Introduction

The twentieth century witnessed dramatic changes in the treatment of severe mental illnesses. Scientists discovered medications that improved some of the symptoms of mental illnesses. The National Institute of Mental Health (NIMH) was created by the U.S. Congress to spur research into the causes of severe mental illness and to develop community-based treatment. The expectation was that with new medications, treatment programs based in the community would flourish and significantly improve the quality of life and productivity of individuals with these disabling medical conditions.

The results of last century's revolution have, unfortunately, fallen far short of hopes. Treatment and support for individuals with serious mental disorders in the community mostly failed to materialize, a result of poor policy decisions, a hodgepodge of funding sources, and inadequate treatment facilities. Stigma has remained a major issue. Jails have become, in many cases, the long-term residence for individuals with severe mental illnesses who once resided in state mental

hospitals. Research advances were modest, due to the limits of technology and scientific knowledge about the brain and biological systems. While new medications emerged, they largely reflected modifications of previous drugs.

To be sure, the recovery movement, scientific advances, and the development of evidence-based interventions were the positive fruits of the last century's mental illness revolution. But the state of research and patient care in the field remains **totally inadequate—and unnecessarily so**. At the beginning of the 21st century, a new mental illness revolution is possible, given the growing knowledge of effective treatments and scientific possibilities for research heretofore unimaginable. Building on the budding knowledge of what works and is possible for people with severe mental disorders, research and treatment system reform, hand-in-hand, can truly revolutionize severe mental illness treatment. The NAMI Research Task Force has formed a strong consensus as to how to reach the goals of recovery, cure and prevention, delineated in the pages ahead.

NAMI's Research Task Force

NAMI's Policy Research Institute convened a task force on research to help identify the ways in which significant advances in research and treatment can be achieved. Members of the task force are listed in the appendix. Specifically, the task force addressed the following questions to provide a roadmap to serious mental illness recovery and cure:

- In light of the public health and human needs as well as scientific opportunities, what are the major research areas requiring investment so as to achieve the most rapid progress possible toward recovery and cure of serious mental illnesses?
- What levels of research investment are required in the near term and over the next 5 years to achieve the identified goals?
- Given the current fiscal and bureaucratic environment, how can necessary investments be secured from the National Institute of Mental Health and other sources?
- Beyond financial resources, what research mechanisms and partnerships are necessary to significantly advance research and translate findings into practice?

NAMI's Research Task Force (continued)

The Research Task Force members, including experts and NAMI members, met on December 16, 2003 at Mount Sinai Medical School, to discuss this agenda. The meeting included presentations by several experts on the research needs in various relevant areas, including basic, clinical, and health services research as well as specific populations, including children and adolescents, aging individuals, and individuals from diverse ethnic and racial backgrounds with severe mental illnesses. The discussion built on efforts by the National Advisory Mental Health Council and other sources. Ten recommendations were developed, which were approved by the NAMI Board of Directors at its January, 2004 meeting in Washington, DC. The meeting's discussion and recommendations are described in this report.

The Human Toll of Mental Illness

Various reports have appraised the impact of severe mental illnesses in dollar amounts and disability costs. Mental illnesses rank first among illnesses that cause disability in the United States and the western world. Suicide, most commonly the result of under-treated mental illnesses, causes more deaths every year than homicide or war. The cost of mental illnesses in the United States is estimated to be \$79 billion each year.

But such figures fail to capture the human toll, the long-term suffering and loss, for the individual with a disabling mental disorder and for care-giving family members and friends. For many of the 5 million Americans with the most disabling mental disorders, educational and vocational progress is severely hampered. The fragmented mental health system together with pervasive discrimination in our society effect formidable barriers to interventions that can help. Terrible consequences too often are the result—incarceration, homelessness, social isolation, victimization, and premature death. Even when treatment is accessed, there are still the limits of current treatments to endure: incomplete relief from symptoms, residual disability, and significant side-effects that accompany even the newest medications for these brain disorders. Throughout this report are descriptions of how individual lives and

families are left reeling from serious mental illnesses and the way it is treated in the United States today. These stories give a glimpse of the pain that mental illness brings, suffering just as palpable and real as that produced by any other disabling and life-threatening illness. How is it then that a compassionate society such as ours can tolerate the state of severe mental illness treatment in the United States today? We cannot. And the results of past research, along with the promise of current and future research, mean that we need not.

Significant Advances Are Possible

Before the present time, it was not possible scientifically to probe and reveal the specific causes and pathophysiology of serious mental disorders. However, advances in genetics, molecular biology, imaging technology, and in other fields are leading to real progress that will translate into more effective treatments with fewer side-effects. Unique to this time in history, scientists are not only able to identify genes linked to severe mental illnesses, but to probe exactly how they lead to symptoms and illnesses. These discoveries will undoubtedly permit better diagnostic classification of these brain disorders, as well as making cure and prevention a longer-term possibility. Some of the promising advances that point to a future of vastly improved treatments are described in this report.

From Mouse Gene Knock-Outs to Live Human Brain Pictures, The Molecular Underpinnings of Panic Disorder Come into Focus

A mouse. A gene. A designer chemical. Images of the living human brain. These are the scientific passages to a better understanding of panic disorder and other anxiety and depressive illnesses.

Scientists at the NIMH developed a tracer molecule that illuminates serotonin-binding sites in the brain. Serotonin is one of the chemicals that nerve cells use to communicate; problems in serotonin communication have been linked to anxiety and depressive disorder and are the target of medications often used to treat these conditions. Using this serotonin-receptor tracer, the researchers went on to examine patients with panic disorder and depression. The PET scans from those individuals showed a significant decrease in specific serotonin receptors in brain regions that regulate emotion.

While this is the first report that illustrated serotonin receptor changes in the living human brain, it builds on a series of studies linking the gene to anxiety. Scientists had previously shown that mice lacking this particular serotonin receptor, in so-called gene “knock-out” experiments, exhibit increased anxiety traits. A more recent report using the “knock-out” mice correlate the anti-anxiety effect of selective serotonin reuptake inhibitors medications, commonly used to treat depression and anxiety, to the birth of new neurons in the mouse brain. This finding is all the more astonishing given that it has been only a few short years since scientists have debunked older theories, showing nerve cell regeneration occurs in the adult mammalian brain.

Other research also points to reduced serotonin receptors in anxiety: Stress induced increases in the stress hormone cortisol were shown to decrease the number of serotonin receptors in specific regions of the mouse brain.

Through molecular genetics, brain imaging studies, the development of chemical probes, and animal studies, scientists are closing in on the underlying neurochemistry of anxiety and mood disorders, surely bringing into focus improved diagnostics and treatments.

Murphy, D.L., et al., “Genetic Perspectives on the Serotonin Transporter,” Brain Res Bull 56(5): 487-94, 2001; Neumeister, A., et al., “Reduced Serotonin Type I A Receptor Binding in Panic Disorder,” J Neurosci 24(3): 589-91, 2004; Santarelli, L., et al., “Requirement of Hippocampal Neurogenesis for the Behavioral Effects of Antidepressants,” Science 301: 805-809, 2003.

Identifying What Is Needed

To date, an inadequate amount of funding has been invested in mental illness research, despite recent gains in funding for the National Institutes of Health (NIH), including NIMH, and private sector spending, from foundations and the pharmaceutical industry. Severe mental illness research funding at the NIH lags significantly behind that of other chronic illnesses, despite the burden posed by these brain disorders and the existing research opportunities.

The current treatment system itself hampers research progress. Mental health care providers, including physicians, receive scant training in the neurosciences and modern biology, let alone the treatments and services known to work. Reimbursement for persons delivering services is shamefully low. The system of care itself is utterly fragmented, obstructing not only the delivery of care today, but the hope of implementing developing technologies in the future. While reform of the mental health system is beyond the scope of this Task Force, the need for such reform is essential for optimal recovery today and scientific progress.

The Roadmap for Serious Mental Illness Research

Although there are many barriers to the research and treatment revolution that is possible, the requirements of modern biomedical research are well recognized and have been outlined in NIH's *Roadmap to Medical Research*. This effort seeks to expedite the process of scientific discovery and translation into improved treatment and health, especially for chronic illnesses. In its *Roadmap* report, NIH spells out an

integrated vision to transform medicine, by developing tools for a deeper understanding of biological processes, promoting interdisciplinary and innovative studies, and reshaping the clinical research enterprise. This vision fits exactly the needs of serious mental illness research and provided an important framework for NAMI's Task Force in creating this roadmap to recovery and cure for severe mental illnesses.

"[Schizophrenia] makes you feel desperate as a parent. I hoped it would be psychotic depression. Isn't that something for a mother to hope for? Something that could be successfully treated? The diagnosis was difficult to accept because schizophrenia was something that wasn't going to go away."

The members of NAMI's Research Task Force came to an extraordinary consensus on the future of serious mental illness research. Serious mental illness research can and must enter fully into the modern age of biomedicine in order for consumers to reap the full benefits. The specific recommendations and rationale follow. Only with adequate resources and leadership will the full promise of serious mental illness research—significant advances in diagnosis and treatment made available to all consumers in an integrated community-based system of care—be realized expeditiously.

Basic to Clinical Research

Research to date has led to reasonably effective treatments for individuals with severe mental illnesses and preliminary knowledge about the genetic, molecular, and neural substrates contributing to these brain disorders. Still, the current understanding of serious mental disorders and their treatments falls far short of the advances now possible.

To date, new psychiatric drug development largely has been the result of serendipitous discovery, after which scientists have sought both to understand the relationship of the drugs to disease mechanisms and to modify the biochemical structure of the agents to improve effectiveness. Review of the new

pharmacologic treatments of schizophrenia illustrates the short-comings of such an approach. Atypical antipsychotic medications variably bind to a host of nerve cell receptors, resulting in unpredictable efficacy in any one individual and various adverse side-effects (table 1).

Table 1—The Receptor Binding Profiles of Atypical Antipsychotic Medications

	D1	D2	D3	D4	5-HT1A	5-HT2A	5-HT2C	α 1	α 2	M1	H1
Clozapine	141	83	200	20	640	2.5	9	4	12	2	23
Risperidone	75	0.3	14	7	488	0.2	26	2	3	>1,000	155
Olanzapine	31	11	--	27	>1,000	5	11	19	228	2	7
Quetiapine	455	160	--	--	>1,000	295	>1,000	7	87	120	11
Zotepine	29	8	6	39	260	3	--	6	540	250	21
Ziprasidone	9	3	7	32	37	0.3	0.5	2	400	>1,000	510
Aripiprazole		0.4			4.4	3.4	15	47		>10,000	67

Table 1 lists atypical antipsychotic medications down the left-hand column and a measure of how strongly each medicine binds to different receptors in the brain listed across the top row. These data suggest why the medications have various side-effects, given the variable binding to several brain receptors.

While significant scientific advances can and do flow from surprising discoveries, the modern paradigm for drug development generally consists of: information developed in large-scale and long-term epidemiologic studies; the identification of molecular targets through basic research; the testing of compounds that influence the molecular targets from chemical assays; animal and human testing; and, large clinical trials that document the outcomes and long-term effects of new agents. In heart disease, Alzheimer's disease, hypertension, and various cancers, this is the tried and true pathway from discovery to improved treatment.

The single largest risk factor for schizophrenia and bipolar disorder is the genetic risk. Significant genetic predisposition is also a major factor in recurrent depression and obsessive compulsive disorder. The sequence of the human genome, known for only two years now, and the emerging map of DNA variation on the genome are opening up an unprecedented opportunity to discover the risk genes that underlie these illnesses. By applying the methodologies of modern genetics, molecular biology, neuroscience and drug discovery, the field of severe mental illness is poised to achieve necessary advances in diagnosis and treatment.

Seizing this opportunity will require a significant increase in financial support and the cultivation of large patient populations for longitudinal and epidemiological studies, simple clinical trials and effectiveness trials, and interdisciplinary research teams.

The need for basic research relevant to severe mental illnesses cannot be overestimated. At present, the understanding of the causes of these brain disorders remains limited and the treatments imperfect. The primary goal of severe mental illness research must be basic discoveries that can significantly advance

treatment options, as well as preventive measures and ultimately cures. While the Research Task Force strongly supports improved dissemination of existing treatments of serious mental illnesses, the penultimate goal is far better treatments. Extensive investment in genetic, molecular, and neuroscience research, involving complex technologies and interdisciplinary teams of scientists, are required to achieve this goal, given the complexity of the brain and the disorders afflicting it. The federal government, and specifically the NIH and NIMH are the key supporters of this basic research.

NIMH Steps Up to the Plate on Schizophrenia Genetics

Long known to have a significant heritable component, the search for schizophrenia genes has proven frustrating to scientists.

Until now.

Scientists have identified several genes that increase the risk of this devastating brain disorder, and are tracing the pathway from DNA to protein to brain structure and function, and finally, brain disease.

One example is the work being done on the COMT-gene (catechol-O-methyltransferase gene). The COMT-gene codes for a protein that breaks down several neurotransmitters. One version of the gene has been linked to schizophrenia. Beyond that, this gene version has been shown to disrupt specific brain regions and to impair specific cognitive functions, brain changes that are also seen in schizophrenia.

COMT-gene is but one of several—GRM3, DISC1, dysbindin, neuregulin—shown to contribute a small but increased risk of schizophrenia and that are being vigorously studied so as to understand the way in which this brain disease unravels the mind and behavior. It is this scientific berth into which NIMH is moving, with a new intramural initiative aimed at tracking down all of these genetic leads in search of a better understanding of the brain factors producing schizophrenia, and how they can be modulated so as to stop the symptoms of this disease or prevent them from ever appearing in the first place.

Akil, M., et al., "Catechol-O-Methyltransferase Genotype and Dopamine Regulation in the Human Brain," J Neuroscience 23(6): 2008, 2003.

Special Section: The Toll of Severe Mental Illnesses

When Severe Mental Illnesses Strike the Young

Darcy Callies was going through a stack of papers in her daughter's room several months ago when she came across a simple drawing on a piece of notebook paper.

Next to the picture, in a child's scribble, Chelsy Griggs had written, "This is a gun. I will kill myself."

Chelsy is 11.

Diagnosed with bipolar disorder and Asperger's syndrome, Chelsy bounces back and forth between two emotions—euphoria and rage. When she's happy, she literally believes the animals can sing. When she's angry, she becomes convinced that the sky will fall, and she lashes out at anyone, anything, nearby.

Several months ago, it was her mother. Chelsy tried to stab her with a carving knife.

In the past, her rages have been directed at her bedroom walls, her own arms, or a toy of her little brother's that she ripped in half.

If Chelsy had cancer, no one would question her parents, or wonder if a little more discipline would keep her in check. When she flies into an unpredictable rage, strangers are quick to point fingers, not understanding that mental illness is to blame....

At times, Chelsy has taken as many as 13 pills a day as part of her treatment, but her rages continue, and her parents are running out of ideas.

Chelsy's mother, Darcy, raised her daughter on her own after Chelsy's father died from a terminal illness during her pregnancy.

Darcy Callies said her daughter seemed to be a pretty typical child until she was about 3 years old. That's when she went to a birthday party where Callies said several young boys molested Chelsy.

Her behavior changed. She started acting out. She started having nightmares.

Darcy assumed her daughter was reacting to the sexual assault. Counselors thought Chelsy had post-traumatic stress disorder. But as months, then years passed, Chelsy's problems just got worse.

By the time Chelsy was in first grade, teachers started telling her mother that something was wrong. Chelsy wet her pants frequently, did poorly in school, seemed so anxious, so angry.

Darcy took her daughter to counselors, pediatricians and psychiatrists. They all had different theories.

“We’ve gone through about 30 diagnoses,” said Callies, 39. “With each diagnosis, there is different medication.”

Yet the rages continued.

As Darcy and her husband, Daniel, gave a summary of the incidents, they have a hard time separating one from the other, looking to each other to remember what caused which rage, such as the one when Chelsy was in second grade. That one brought police officers to the house.

Chelsy was out of control and her parents couldn’t calm her. Over the years, they’d learned how to safely restrain her physically, how to talk her down. But that time, nothing worked. Chelsy pushed her stepfather down the stairs, bit and kicked her mother, then threatened to kill her.

Darcy called the police.

When the first two officers arrived, they immediately called for backup. Chelsy was spitting on them, cussing at them. They couldn’t get her out of her room, Darcy Callies said.

“Her adrenaline was amazing. She had more strength than 10 men that day,” she recalled.

Finally, the officers shackled Chelsy’s hands and feet, managed to get her into the police car and took her to the hospital.

Chelsy spent a month at the Colorado Mental Health Institute at Fort Logan.

She came home to a bedroom with nothing more than a bed, a light and a dresser. She couldn’t have stuffed animals because she once ripped the eye off a teddy bear and used it to cut herself.

Safety pins were hidden, kitchen knives were locked away. Even lotion had to be put out of reach or she tried to drink it.

“Everything became a weapon,” Darcy Callies said...

Two years ago, Darcy Callies had no choice but to quit working because she was constantly having to leave her job in restaurant management to pick Chelsy up from school or take her to a doctor.

She blamed herself, but wondered why none of her other children had similar problems. Then she blamed her husband.

“I wouldn’t let him do anything,” Darcy said. “If he looked like he was going to raise his voice, I would jump up and get in his face.”

Daniel Callies said he blamed her right back. Darcy was too lenient, made too many excuses, Daniel argued.

The couple fought. They talked about divorce.

“I’m falling apart because my kids are falling apart, then our marriage started falling apart,” Darcy said.

Endless struggle...

[A] therapist who has worked with the Callies’s in their home twice a week for the past several months said it’s not uncommon for parents to struggle over a difference in style, and those issues are compounded with a mentally ill child.

The Callies’s, the therapist said, are trying to find a way to acknowledge Chelsy’s illness without excusing unacceptable behavior. That’s tough, he said.

“I think that they struggle a lot. I think they struggle personally. I think they struggle parentally,” the therapist said. “I think they’ve worked very hard on this, and it’s been a difficult and long road for them.”

Daniel and Darcy Callies are beginning to work together, but Chelsy’s illness still strains the family.

They suffered another setback this fall when Daniel was laid off from his computer job. The family had to move from their five-bedroom home into the basement of Darcy’s niece’s home.

That didn’t help Chelsy’s anxiety, and she already was struggling to adjust to her first year in public school after her mother decided she was ready to leave the day treatment program where she had spent the past two years.

Still, Chelsy weathered the changes well—until November. That’s when she suddenly refused to enter her classroom.

She told her mother the other children had laughed at her, but neither Darcy Callies nor school officials seem to know what really triggered the problem.

One day, Darcy tried to help by walking Chelsy into the classroom, but when Chelsy got about 15 feet away, she froze, then wet her pants. She begged not to go in the room, Darcy said.

For a while, school officials allowed Chelsy to study in the principal’s office or the main office. After a couple of weeks, though, when they still couldn’t get Chelsy back into the classroom, school officials recommended transferring Chelsy to a more therapeutic setting.

Darcy Callies spent nearly a month trying to find another school, and after hours of meetings and research, she found another public school willing to accept Chelsy.

“Hopefully, it will work,” she said...

Making sure Chelsy gets the care she needs has consumed most of the Callies’s spare time, and with the legislature’s recent cuts to Medicaid, their situation could get worse.

Now, Medicaid will pay for only 45 days of hospitalization each year, which in a bad year, won’t begin to cover Chelsy’s needs. Between emergency room visits and stays for long-term treatment, Chelsy once spent more than two months in and out of hospitals.

“What’s going to happen on the 46th day?” Darcy asked.

The couple spends hours on the Internet, researching medication, looking for services, hoping to find something, someone who can ease their burden.

They rarely go on dates. Vacations are unheard of. Even time alone at the house is rare.

And Darcy Callies wonders if she and her husband will forever care for a daughter she had once hoped would become a doctor.

“I had all kinds of hopes and dreams for her,” Darcy said. Now, she said, “the most I can hope for her is to live in an assisted living program. I don’t see her succeeding 100 percent on her own and having a family and having kids.”

Daniel and Darcy Callies have joined a support group where dozens of other parents in similar situations share their grief, and that has helped.

Mostly, though, they wish others knew more about mental illness. Then, other parents might be more willing to have Chelsy play at their house. The Callies’s might not be so nervous to take her to a restaurant or the grocery store. They might not be so worried that any outburst will bring criticism of their parenting skills.

Chelsy is sick, her mother said, and her illness makes her act differently. But she’s still a child who needs friends, birthday parties and parents who love her.

“She’s a really lovable kid. I don’t want people looking at her like she’s a monster,” Darcy Callies said.

SOURCE: Reprinted with permission from “Young and Mentally Ill; State Services Dwindling for a Disease Few Understand,” Gabrielle Crist, Rocky Mountain News (Denver, CO), January 3, 2004.

Confronting Depression in Older Age

Depression rises like mist from a gentle meadow and pours unseen under closed doors, around the edges of windows, darkening the moment of content, even happiness.

It last invaded my life as sleepiness, not the response to hard work, but the unexpected tumbling down a black crevasse after a good night's sleep. And after each waking, I yearned for another escape into sleep.

In other intrusions, the lights dim, the walls grow closer, the ceiling lowers, and, as the room shrinks, the presence of those around me fades and recedes as if seen through binoculars turned backward.

I'm not talking about the understandable sadness that follows the death of a loved one, the loss of a friend that follows saying something that can't be unsaid, the despair that accompanies failure, the melancholy that may be the response to an unexpected diagnosis or yet another symptom of aging.

These depressions of mine are not the major, life-destroying attacks that overwhelm, but guerrilla raids that strike and then just as suddenly disappear in hours or days. They are mild compared to what others suffer, but that is of less comfort than it should be while the weight of depression presses down harder and harder.

My depression attacks on sunny days, when I am surrounded by those I love and who I know love me, after a success, when there is good news, not at the funeral but at the celebration.

Sometimes it arrives as a strange freezing in the center of my stomach; other times as a sudden, lurching detachment from those around me; often as a subversive feeling that those who love me do not or should not.

It is hard to hide this sudden darkness from those closest to me, and difficult for them to understand. People like my new book, recognize me with an honor, find me worthy. Yet I am depressed.

Mother tells me from her grave that I do not deserve the award, reward, or attention I am getting. And I agree. I am worthless.

Depression is often an irrational reaction to life. I withdraw to bed or the other room, seek loneliness exactly because I so need love, wrap myself with inappropriate self-pity.

At first, I reject the comfort and reassurance offered by those closest to me. Friends become bored with my irrational despair and tell me to snap out of it and get on with life, reminding me of those who have far greater problems. They do not realize that I am, at that very moment, lecturing myself, saying the same things, trying to snap out of it and rejoin the human race.

Father took to bed when he suffered a business failure, and the family hid his "nervous

breakdown.” I felt the shame of this secret. Mother veered unexpectedly from anger and hopelessness to energy and fearful jollity, and it was accepted as the way of women. They needed help, but there was none, not for Scots, not for Baptists in those days.

Today there is help and no shame, not among the generations that follow us. We are enlightened. I met a neighbor in the doctor’s office, and he said his head was “broke,” the way he would speak of a broken leg. I report my bouts of depression because so many of the elderly suffer similar attacks or worse, yet deny their illness.

I had never in my first 70 years suffered depression. I was unprepared for its subversive, terrorist attacks, but I sought help. The first psychiatrist gave me a miracle pill but little else. I moved on. My second psychiatrist gave me pills and understanding, support, and a healing friendship.

When we, who have been brave and self-sufficient all our lives, suddenly find ourselves adrift in a sea of despair, we must cry for help and grab the lifesaver that is immediately available. Therapy works. We must be fair to ourselves - and to all those who stand helpless loving us.

SOURCE: Reprinted with permission from “When Darkness Falls Despite the Sun’s Rise,” The Boston Globe, July 17, 2001.

Shooting for Recovery

Basketball is more than a game to Julian Swartz.

It’s a tightrope that traverses life and death. It protects and torments the 22-year-old sophomore who has battled a noxious medley of obsession, compulsion, panic and depression since childhood.

Swartz is on his third comeback attempt after taking a sabbatical from the sport following the University of Wisconsin’s trip to the Final Four in 2000.

The other two comebacks almost killed him.

He left school and enrolled in a psychiatric program after he attempted to commit suicide twice in one day upon his return to the Badgers in 2001.

Last fall, he gave hoops another try at Wisconsin-Green Bay, but that comeback also ended in the emergency room. Doctors told him he was lucky to be alive after an overdose of antidepressants.

He quit taking his medication for obsessive-compulsive disorder and he swore off basketball, which had so richly blessed yet so dearly burdened Swartz since he bounced his first ball with the natural talent befitting a former college player’s son.

Wisconsin-Green Bay coach Tod Kowalczyk made Swartz a student assistant coach. But because

they were short on bodies, especially big bodies, the 6-foot-7 forward spent six weeks practicing with his former teammates.

And the lure of the hardwood simply proved too great for the 1999 Wisconsin Associated Press high school player of the year.

He decided to move back home with his parents in Waukesha so he could play at Carroll College, a Division III school just down the road.

“My first thought was, ‘Why?’” said Greg Monfre, a junior at Wisconsin-Green Bay and Swartz’s best friend since seventh grade. “Why do you want to put yourself through this again? Just be a regular college student, get your degree.”

But Swartz wanted to keep playing. The only place he felt he could safely do that was back home, sheltered by his family and friends and steeled by his faith in God and basketball.

He is still shedding the rust and the 15 pounds he collected during his 2 1/2-year furlough from college competition. But since Swartz’s debut a month ago, the Pioneers have won more games than they did all last year and have gone from a rebuild to a contender in the Midwest Conference that includes schools from Wisconsin, Illinois and Iowa.

Swartz said his greatest accomplishment wasn’t helping the Badgers get within an eyelash of the Division I national championship three years ago but scoring 20 points in a loss to Ripon in his Carroll College debut last month.

“He told me it’s the first time in a long time that he’s really enjoyed playing basketball,” said David Schultz, Swartz’s new coach.

Swartz knows it’s a big risk, playing again.

But if there’s anything more powerful than the mental illness that traps him in a cycle of repetitive thoughts and multiplying worries, it’s his love for basketball.

When he was a boy, OCD made Swartz wash his hands hundreds of times, get up at all hours of the night to check the locks on the doors and wipe down the bathroom for an hour after showering lest anybody slip and fall.

Now, intrusive thoughts, which can last hours and even days, swipe his focus and concentration by day and steal away his sleep at night.

They tell him that something he did or said offended somebody. He knows it’s a lie, but he hears it over and over and over again until he starts to believe it.

“I don’t know how other people’s minds work, but I have nonstop thoughts in my head,” Swartz said. “It’s like a clock. From the moment I wake up until the moment I go to sleep, it just keeps

ticking.”

And it ticks loudest when he’s playing basketball.

“The more I love doing something, the more it tries to make that miserable,” Swartz said.

“Without the game, it’s a whole lot easier, I’ll be honest with that. But basketball is something I’ve done ever since I was born and I think the love I have for it is illustrated by the number of times I’ve come back.”

And the powerful nature of the disease is evidenced by the equal number of times he’s been forced to retreat.

OCD affects, to varying degrees, one in 50 Americans. Sufferers become trapped in a cycle of repetitive thoughts and behaviors that they might realize are irrational but which they find difficult to curb.

“The nature of the illness is one never knows what’s going to happen the next day,” said Swartz’s mother, Kathleen.

What’s to say Swartz’s latest comeback won’t end like the others, in another hospital room? Or worse?

There are no such guarantees, Swartz attests.

“I really want to say - probably not at 100 percent, but I’m working for that - that suicide in all realms is not an option any longer,” Swartz said. “That’s something I’m really working hard at.”

He swears he wasn’t trying to kill himself when he swallowed two bottles of pills last fall.

“I couldn’t bring myself to go to a morning workout and I just felt like I needed to do something, you know?” Swartz said, still struggling to understand it all himself.

“That illustrates the power of the illness. You end up doing things that later you look back on and wonder, ‘Why?’”

But Swartz readily admits he had every intention of dying two years ago when he returned to Madison.

“I was going to try to make it look accidental. And I tried and I couldn’t do it,” he said. “It’s not a decision I made. It was a result of not being able really to stop my mind. You look at it, there’s only one way to stop that mind from ticking.”

Kathleen and her husband, William Swartz, who ran track and played basketball at Wisconsin-River Falls from 1959-64, welcomed their son’s return to home and to the hardwood with a mixture of pride and prayer.

“Sure, as a mom it scares me. But I think it’s exciting to see him doing something he truly loves to do,” Kathleen Swartz said.

Swartz’s family has always been his sanctuary, cheering him on during his athletic and academic achievement and soothing him during the depths of his depression.

“As a family all you can do is be there for support through the good times and the bad,” his mother said. “Home is a wonderful place for him and the community is so kind and understanding and Carroll has given him a wonderful opportunity. Whatever happens, we know he’s in an environment that’s nurturing.”

He needs every bit of that support.

Last month, Swartz had terrific games on successive nights, scoring a combined 44 points as Carroll beat Lake Forrest College and Monmouth College, but he described the weekend as “absolutely miserable.”

The one memory he takes from his 18-point performance against Lake Forrest is the lone free throw he missed, which he blames on a meddlesome idea rattling around his head.

It stayed with him as he tossed and turned all night.

“I had to get my mom out of bed a few times just to calm me down,” Swartz said.

Daylight only brought more suffering.

“I woke up, battled it up until the game, probably even during the game and then to go out and play well, people see from the outside, but they don’t see how much work it is just to be able to play in the game, let alone do well,” Swartz said.

It helps that his new coach is no stranger to Swartz’s game or his illness.

Schultz met the Swartz family when Julian Swartz was just a 6-year-old gym rat. He coached against Swartz in some epic matchups between the city’s West and South High School powerhouses in the 1990s.

“That’s a big reason why I feel so comfortable at Carroll,” Swartz said. “I remember playing 1-on-1 with him when I was a kid.”

So, Schultz, who took over the Pioneers program this season, knows all about Swartz’s strengths and weaknesses - his teams were 7-3 against Swartz’s in high school - and his trials and tribulations.

“He doesn’t have to go into a big explanation on things,” Schultz said.

Any small college coach who had a Division I player drop into his lap at midseason would be thrilled. Schultz sure was.

“There was a mixture of excitement in terms of what he could bring to the team but also some uncertainty in terms of where he was at a personal level,” Schultz acknowledged.

After all, it had been 32 months since Swartz last played a game, against Michigan State in the 2000 national semifinals.

“But since he’s gotten here, he’s like every other player,” Schultz said. “He wants to do well, he wants the team to do well and he wants to fit in.”

He’s 3-for-3.

His versatility made for a smooth transition.

“He’s not just a low-post guy, he’s not just a shooter,” point guard David Jooss said. “He does a little bit of everything and it’s pretty easy to mix in a new guy when he’s a complete player like that.”

Swartz, who averaged a team-best 23.8 points and 7.5 rebounds over his first eight games back, is the quintessential athlete who makes everybody around him better.

He’s so athletic and such a good shooter that big centers have to go out to guard him, leaving the lane open for his teammates to sneak inside for easy baskets.

“He has told us, ‘I’m 15-20 pounds overweight,’” Jooss said. “And we’re like, ‘You’re pretty darn good right now.’”

Just wait until next year, after a summer of conditioning, his coach said.

Swartz doesn’t look that far ahead.

He wants to finish his education - and his eligibility - at Carroll so he can become a Christian psychologist, treating OCD patients through the ministry and his own experiences.

His focus, however, is on much more immediate goals:

Get through today, then tonight, then tomorrow.

“As long as I play the game of basketball it’s going to be difficult,” Swartz said. “It doesn’t matter what level. It doesn’t matter where.

“OCD is something I’m going to battle every day. I guess it’s my life work, my project.”

SOURCE: Reprinted with permission from The Associated Press, "Game Is Both Friend and Foe to Basketball Player with Mental Illness," February 2, 2003.

Struck Down by Schizophrenia

Adam Samec was a creative, sensitive and gentle child.

As a young man, he loved to paint and write music, songs and poetry. He taught himself to play guitar and dreamed of becoming an anthropologist.

He was 20 when he killed himself.

Adam left behind a devastated family, along with more than 30 journals, songs, drawings and paintings that reveal the inner turmoil, struggle and pain of his illness, offering insight into the thought processes of a young man diagnosed with schizophrenic affective disorder/depressed type.

"Looking at all of it, I think he left behind something very special that could help professionals in the mental health field and help parents who find themselves dealing with a child's mental illness," says Adam's mother, Vicky Reicks of Cresco. "I can't pack them all away. It's a gift he left behind, and within his writings, he left behind messages to me. He knew his mom would read these journals."

Adam shot himself on April 11, 2001.

Vicky couldn't bear to look at the journals until last winter, and what she read on page after tightly written page were not ramblings, but a kind of poetry, vivid word portraits tracing the chronology of her son's illness, the medications, the voices he heard in his head, the angels and demons who sat on the edge of his bed or hovered near the ceiling regaling him with tales, his intense loneliness and isolation, and eventually, his flirtation with suicide.

"I had grown ill over time, though I took my pills as a good boy should. I was fretting now terribly, unable to think, rest, my moody temperament coming forth. More pills, more days, it would all be better. Found little rest in my routine, knowing that my purpose was also to the point of breaking. ... Dosage after dosage of medication would not be allowed to take hold, for I was on the outside, severely incapable of change. ... The doctors had seen nothing but my dismal face and thus subscribed me to a long list of takers of a specific drug meant to target symptoms which I had, though the disease was all around a different story."

The notebooks, computer printouts and loose-leaf binders are scattered across the dinner table. Passages are marked with yellow Post-it notes, where Vicky has made notations. This passage, she points out, is about practicing suicide, and this entry was written when Adam was hospitalized, and here is a direct appeal to his mother to forgive him.

"He was so lonely. Everyone went their own way in the end. He lost his friends, he lost himself

and he didn't know what to do," Vicky says. "There is so much here, I think there's enough material for a book. I'd like to tell Adam's story in some way, to help other people because there is so much stigma attached to mental illness."

Adam was first hospitalized in 1999. The high school student had become increasingly withdrawn and his personality changed. With a mother's instinct, Vicky knew something was wrong. Although she respected his privacy, she sneaked a peek at his writings and was disturbed by what she read. A crisis was brewing, she felt it in her bones.

Vicky sought advice and intervention from doctors and guidance counselors. Adam's behavior was dismissed as a teenage phase. He was going to school, had a girlfriend, held down a part-time job. She worried too much, and perhaps should seek counseling herself. Adam refused to see a doctor despite his mother's entreaties.

Then she received a phone call from his girlfriend's parents. Adam was having an anxiety attack and needed medical help.

"He was committed to Allen Hospital on Aug. 28, 1999, and that was the beginning of a long, painful and rough journey," says Vicky.

He was hospitalized for 19 days and received electroshock therapy treatments for depression. In late 1999, he was finally diagnosed with schizophrenic affective disorder/depressed type.

"It makes you feel desperate as a parent. I hoped it would be psychotic depression. Isn't that something for a mother to hope for? Something that could be successfully treated? The diagnosis was difficult to accept because schizophrenia was something that wasn't going to go away," she recalls...

Vicky accompanied her son to every doctor's appointment.

"He was hurting. Thoughts flowed out of him and he wrote constantly. I found out he was cutting himself on his chest, arms and legs. He showed me and I was horrified. He said it was the only way he could feel anything," Vicky says, "and his inner voices told him he deserved to suffer."

Adam wrote about the cutting episodes, swallowing countless pills in rainbow hues and alternating feelings of hopelessness and acceptance. He also described episodes of hospitalization and interactions with doctors, including "faking them out" while recognizing he knew they were aware he was faking.

"Eaten up by pills and pimples and Prozac, I simmer down from my cues, shifting down, someone always there ... I alter my views as I alter my face ... Help me not to fall down."

Medication improved Adam's condition, and he continued to write, draw in ink and charcoal and paint watercolors. He presented a self-portrait to his mother for Mother's Day, and drew numerous other self-portraits at various stages of his illness. He also painted demons and angels

and other images, mingling bright and dark colors into startling, affecting images.

Adam was hospitalized off and on for a total of 135 days in a 1 1/2-year period. His medication changed numerous times, often causing other medical problems, such as stomach ailments. He enrolled in a research program at the University of Iowa in Iowa City before deciding not to go through with it. He was hospitalized in Fall 2000 for nearly a month. While he was gone, someone broke into his apartment and stole his guitars and amplifiers.

In February 2001, Adam attempted suicide by taking a medication overdose. His stomach was pumped and he was hospitalized.

Her son's suicidal thoughts never stopped, Vicky believes.

"It was a way to end the pain. His mind was never at rest. He was never at peace. The illness brought him to his knees. My ex-husband, Adam's father, still can't read the journals because it's too sad and painful for him."

Adam shot himself on April 11 in his father's home. His brother discovered his body. The final entry in Adam's last journal reads:

"I hope that they will find my body cool, warmed only by the remaining heat under the blanket. Breathless, I lie upon the pillow drooling no more, cotton-mouthed from all of the drugs. My body no longer functions and my heart is dead now; never had room for anyone else anyway. Don't let them find me all insecure like this, but instead, let them find me secure with death."

Vicky says, "All of the doctors, all the pills, all of the treatments. I'm left with the thought that, in spite of it all, we somehow let him down. I have a lot of bitterness about a society that still treats mental illness as something that should be hidden away in the dark. When you have someone in your family who is mentally ill, people walk the other way. If he'd had cancer or some other disease, they would be more sympathetic and understanding."

Figuring out what to do with his writings and artwork is something tangible that keeps mother connected to son.

"All of this," she says, gesturing at the journals, "multiplies my pain. I think about my child suffering through this and it just about kills me. I just want him back, to hug him and tell him how sorry I am that this happened to him."

SOURCE: Reprinted with permission from The Associated Press, "Journals, Paintings Trace Journey into Schizophrenia," January 8, 2004.

A Mexican American's Path to Recovery

I am a third generation Mexican American. I grew up with my mother and extended family and never knew my father. My mother was a teenager with undiagnosed mental illness. Mine is a family history of mental illness and alcoholism that has gone on for generations unchecked.

The first time I was homeless I was seven years old. Most of my childhood we spent moving from house to house, from family member to family member. At one time we lived in a van in California, and my three baby sisters and I lived off of food banks. When we lived in another part of California, we had run out of food and had been living off of potatoes for months. One day, my sister was crying in the front yard and a neighbor asked her what was wrong. When she found out that we did not have any food she bought us some. From then on she would drop in and always have something for us to eat in hand. While growing up, at best we lived in substandard housing in very dangerous neighborhoods with gangs, drugs and prostitution all around us.

I didn't know it back then, but I too have a mental illness; I am diagnosed with bipolar disorder and post-traumatic stress disorder. After a tremendously challenging childhood and adolescence, my early adulthood did not fare much better. I continued to have difficulties finding stable housing, which became harder to deal with when I married and had three children.

We attempted to live off a meager existence of \$670 a month. But we couldn't find stable housing. The local housing authority had a five-year wait list. To stay off the street, we lived with various family and friends, sometimes renting a room in their home. We applied for every assistance program we could find, but found ourselves caught in a frustrating loop. I was denied low-rent Section Eight housing because my credit was bad, the result of my undiagnosed and untreated illness. No one wanted to rent to us because I did not have a stable work history, or bank account, or references. But when you don't have an address or phone number, you can't give a contact number for jobs. In addition, it also makes it difficult for clinics to make an appointment with you. Throughout this frustrating process, my family and I lived in dangerous neighborhoods where it was not uncommon to hear the crackling and pop of assault rifles on a regular basis. One of the hardest things I faced was having to teach my children to fall flat to the floor when gunshots rang out in the neighborhood.

Thankfully we finally qualified for assistance from the county. We were then able to rent a studio apartment and everything turned around. Once I was able to manage my illness and have some stability in my life, I began to volunteer at a local homeless outreach clinic so I could give back to others who were going through what I had. This has been extremely gratifying for me, especially since I speak Spanish and can help bridge the language and cultural gap that makes getting help so difficult for many people.

SOURCE: Excerpt of comments presented by Ramiro Guevara, consumer advocate and national project director of In Our Own Voice, as published in "Shattered Lives: Results of a National Survey of NAMI Members Living with Mental Illnesses and Their Families," July, 2003.

Clinical Research

Noting that treatment advances will fail to improve consumer outcomes without successful testing and dissemination, the Task Force's discussion of clinical research highlighted the severe limits on such studies in the current environment. In essence, the clinical research data that exist today derive from short-term studies of limited generalizability to real world practice. The most common funding mechanisms used by the NIMH fail to create the clinical research infrastructure needed for testing of interventions in the real world. Corporate sponsored studies are aimed at achieving approval by the U.S. Food and Drug Administration (FDA), and, therefore, also fail to create the kinds of knowledge needed to help stake-holders understand the most appropriate use of new interventions. Private foundations generally have not had the resources to support a large clinical research infrastructure. And while the U.S. Department of Veterans Affairs (VA) has moved forward in this area, the patient populations represented in that system of care are fairly distinct from the larger population.

When he was a boy, OCD made Swartz wash his hands hundreds of times, get up at all hours of the night to check the locks on the doors and wipe down the bathroom for an hour after showering lest anybody slip and fall.

Now, intrusive thoughts, which can last hours and even days, swipe his focus and concentration by day and steal away his sleep at night.

"OCD is something I'm going to battle every day. I guess it's my life work, my project."

The result, as noted, is the lack of information to guide real world practice and the lack of data to inform policy issues upon which vast sums of monies are spent. Other fields have invested in large so-called practical clinical trials—that is, large-scale trials that compare clinically relevant alternative interventions among diverse populations of study participants in real world practice settings, collecting data on health outcomes meaningful to consumers, their providers, and policy-makers (table 2).

Table 2—Features of Practical Clinical Trials

- Compare clinically relevant alternative interventions
- Include a diverse and representative population of study participants
- Conduct studies at heterogeneous and representative practice settings
- Simulate actual treatment conditions
- Collect data on a broad range of health outcomes that are clinically meaningful

For example, results from a 42,000 subject study of various approaches to heart attack prevention—ALLHAT (Antihypertensive and Lipid-Lowering Treatment to Prevent Heart Attack Trial)—showed the benefits of a generic diuretic as a first line of treatment to prevent major cardiovascular events. Another example is the Women's Estrogen-Progestin Lipid-Lowering Hormone Atherosclerosis Regression Trial (WELL-HART) that tested the impact of hormone replacement therapy in preventing coronary heart disease in 226 post-menopausal women. Another study of women's health—The Women's Health Initiative RCT—showed in a long-term study of more than 16,000 post-menopausal women that

hormone replacement therapy increases the risk of breast cancer.

In the past few years, the NIMH has moved to create large practical trial networks aimed at answering questions that can truly inform clinical practice and policy-making. Among these studies is CATIE—Clinical Antipsychotic Trials of Intervention Effectiveness—that aims to discern the relative effectiveness of atypical antipsychotic medications and traditional neuroleptics. This study, to which a variety of pharmaceutical companies have contributed medications, involves 1,500 individuals with schizophrenia and will probe a variety of outcomes, including symptoms, functioning, substance use, cost, treatment adherence, and others. It also includes a genetics initiative. CATIE, and other large clinical trials focused on mood disorders in adolescents and adults recently initiated by the NIMH, mark an important maturation for the psychiatric research field and provide a critical infrastructure for answering a variety of other questions, including issues around adherence, polypharmacy, recovery promotion, and early detection and prevention. The Research Task Force concluded that the continuation and expansion of these efforts on the part of NIMH, akin to other fields of medicine, are essential for the evolution of the mental health field.

Health Services Research

The goal of health services research is to determine how to translate effective interventions into real world practice and optimal outcomes for consumers. Research needed to achieve this goal spans studies on the financing and organization of mental health services, the evolution and implementation of evidence-based practices, ways to improve access, cultural competence, adherence, and outcomes, the

optimal use of medications and psychosocial/rehabilitative technologies for diverse populations and problems, and treatment of co-morbid conditions, including substance abuse and medical problems (table 3).

Table 3—Health Service Questions Relevant to Severe Mental Illnesses

- What are the optimal ways to structure the financing and administration of services within a given budget?
- What are the optimal ways to roll out evidence-based practices in an ongoing, unbiased, and timely fashion, without disparities rooted in culture, ethnicity or race?
- What information technologies can improve education, access, adherence, follow-up, training, and quality assurance?
- Beyond ACT, what other models of care management are appropriate to differing populations?
- How can appropriate medication use be optimized?
- What interventions work best for co-occurring conditions (such as medical, psychiatric, co-morbidities, and sequelae to trauma) and residual symptoms and cognitive deficits in severe mental illnesses?
- How can long-term improvements in social and vocational functioning be achieved?
- What role does peer-to-peer, family-to-family, and illness-self management play in achieving recovery?
- What facilitates access and engagement in treatment to eliminate health disparities?
- How can optimal adherence be facilitated?
- What mix of housing and supports should be offered to reduce psychiatric crises, hospitalization, incarceration, and homelessness?

The use of information technologies in achieving these goals, as well as workforce training and quality improvement efforts, and the expanded role of consumers and families in service delivery are also important components of the health research agenda.

The Research Task Force noted that NIMH should not be the only agency involved in supporting this transformational health services research agenda; there must be much greater participation and support from other federal and state agencies financing and directing the service system, as well as academic centers and community providers. Currently, and as noted in the President's New Freedom Commission report on mental health, there is a panoply of agencies involved at the federal level in the finance of services for individuals with serious mental illnesses, with the federal government alone operating 42 programs for such services. While there is a strong incentive for these

agencies to work together to support recovery-oriented, evidence-based practices that are efficient and complimentary, different agencies typically create policies and reimburse services at odds with the evidence-base and with each other. The research supported by the various agencies is often at odds as well. There was strong agreement on the Research Task Force that a federal entity, which coordinates psychiatric services research and facilitates the implementation of a truly integrated system of evidence-based practice for individuals with severe mental illnesses, must be created. Without such an entity, funding will remain inadequate, a confusing array of research initiatives will continue, evidence-based practice implementation will sputter along, resources will continue to be wasted, and integrated, community-based care will remain a distant goal. Health services research is where recovery can be made possible in the real world.

Genetic Sleuths and OCD

Monk is not the only successful sleuth when it comes to obsessive compulsive disorder or OCD. Scientists have found a mutant version of a gene linked to OCD, the human serotonin transporter gene (hSERT).

As is true of any good detective story, the hSERT-OCD connection brings with it some surprises. The gene mutation links up with not only OCD but also other psychiatric disorders, including eating disorders and pervasive developmental disorders such as Asperger's Syndrome and autism. The study also found that more severe symptoms occur in individuals who have two different mutations within this gene, a rare genetic mechanism. The gene itself codes for a protein that moves the transmitter serotonin into cells; its function seems to be enhanced by the observed mutations, another rarity. And while SSRIs are a commonly used form of treatment for OCD, individuals with the mutations in this study were unresponsive to the medications.

Given the disability costs of OCD and the limitations of current treatments for many individuals suffering from this condition, the genetic and neurobiological advances briefly summarized here point to new targets for treatments and better diagnostic tests.

Kilic, F., et al., "A Human Serotonin Transporter Mutation Causes Constitutive Activation of Transport Activity," Molecular Pharmacology 64(2): 196-8, 2003; Ozaki, N., et al., "Serotonin Transporter Missense Mutation Associated with a Complex Neuropsychiatric Phenotype," Molecular Psychiatry 8(11): 933-6, 2003.

Clinical and Services Research in Children and Adolescents

The extent of serious emotional disturbances in children and adolescents in the population and the risk factors that contribute to these problems are fairly well documented. So too is the lack of access to treatment for many young people with a mental illness.

For some conditions affecting children and adolescents, such as certain types of mood

disorders, much remains to be learned about the presentation of the disorders and what constitutes effective treatment. For other disorders in this population, such as ADHD, much is known about what interventions help, but, as noted, access to evidence-based interventions is severely limited. In fact, there is little correlation between the interventions shown to work and what is implemented in the service system (table 4).

Table 4—Factors Related to the Implementation of Child Interventions				
Intervention	Formal Training Available	Special Financing	National Organization Standard	Evidence Controlled Research
Family Preservation	–	Federal legislation	+	–
Case Management/Wraparound	+	Medicaid waiver	–	+
Treatment Foster Care	+	Joint funding by mental health and child welfare	+	+
Multisystemic Therapy	+	–	+	++
Eye Movement Desensitization and Reprocessing	+	–	–	Minimal
<p><i>Table 4 shows the presence of various factors that can influence the implementation of treatments for children. Note that the presence of evidence is only one factor, and that it is not necessarily the strongest one.</i></p>				

Table 4 shows that the implementation of various interventions, listed in the first column, relates far more to formal training, special financing arrangements for the intervention and national organization standards, than to the presence of evidence showing the interventions effectiveness. Key issues for research include:

identification of risk processes that can guide intervention development; treatment development research, including basic research studies and the development of clinical trial networks in areas of highest need, such as bipolar disorder, eating disorders, and childhood depression; research to promote the dissemination,

implementation, and sustainability of effective interventions, including the development of implementation resource kits; study of the prevalence, risk, and distribution of needs and services in children and adolescents, especially taking advantage of the National Child Study headed by the National Institute of Child Health and Human Development; studies on the long-term safety and efficacy of medications in children and adolescents; services research aimed at informing optimal policy and practice; and better coordination among federal and state agencies in implementing services for children and adolescents.

Chelsy is 11.

Diagnosed with bipolar disorder and Asperger's syndrome, Chelsy bounces back and forth between two emotions—euphoria and rage... [Chelsy's mother] took her daughter to counselors, pediatricians and psychiatrists. They all had different theories.

"We've gone through about 30 diagnoses," said [her mother], 39. "With each diagnosis, there is different medication."

Yet the rages continued.

Aging Research

The Task Force noted the extensive opportunities for fruitful research that exist in the field of aging research, and the public health importance of this research, as shown in the recent National Advisory Mental Health Council work group report on the subject (table 5).

Unfortunately, aging research is a field that has remained stagnant in terms of funding and attracting investigators over the last several years. Research priorities addressing the public health need and opportunities that exist, include: research aimed at reducing

Table 5—Public Health Significance of Serious Mental Illness in Aging Population

- Changing demographics of the United States
- Public health burden of mental illnesses in later life is great and will increase
- High out of pocket costs for mental health care among the elderly

suicide in older Americans, who are at highest risk in the population; the development of evidence-based practices for the treatment of severe mental illnesses among older individuals; study of the unique aspects of mental disorders in aging populations ranging from age- and illness-related changes to pharmacokinetics, cognition, and medical co-morbidities; the dissemination and implementation of intervention approaches that have been shown to work among the elderly, such as depression care-management; and taking advantage of age-related behavioral neuroscience leads. The intersection between aging research and severe mental illness is significant. For example, at the present time there is not a single funded study examining bipolar disorder in older individuals. The Task Force endorsed the implementation of various methods to attract investigators to the field and infrastructure development such as clinical research trials involving this population.

I had never in my first 70 years suffered depression. I was unprepared for its subversive, terrorist attacks, but I sought help...I report my bouts of depression because so many of the elderly suffer similar attacks or worse, yet deny their illness.

Health Disparities

The Research Task Force noted how critical it was for research and system reform to redress disparities in access to mental health care. Ethnic and racial minorities are less likely to get mental health care when needed, reflecting a lack of health insurance as well as a lack of services from providers of various ethnic/racial backgrounds. In addition, individuals from ethnic and racial minorities receiving mental health services are less likely to receive high quality evidence-based care. Future research must focus on interventions that raise awareness of serious mental illness and its treatment in various ethnic and racial groups, as well as ways to enhance access and acceptability of mental illness treatment in different populations. Service system reform must make ending health disparities a top priority as well.

I am a third generation Mexican American...My mother was a teenager with undiagnosed mental illness. Mine is a family history of mental illness and alcoholism that has gone on for generations unchecked.... I didn't know it back then, but I too have a mental illness; I am diagnosed with bipolar disorder and post-traumatic stress disorder.... Once I was able to manage my illness and have some stability in my life, I began to volunteer at a local homeless outreach clinic so I could give back to others who were going through what I had. This has been extremely gratifying for me, especially since I speak Spanish and can help bridge the language and cultural gap that makes getting help so difficult for many people.

General Issues

As noted above, the Research Task Force acknowledged that the vision and initiatives proposed under the NIH's *Roadmap for*

Medical Research were remarkably consistent with severe mental illness research needs. For example, the basic science component of the Roadmap, which builds on the opportunities of the post-genomic world of research, affording infrastructure support to probe genes, proteins, and smaller molecules involved in biological systems, is central to research progress in severe mental illnesses. Its emphasis on interdisciplinary research also is an important requirement of severe mental illness research, involving chemists, physicists, neurobiologists, geneticists, statisticians, computer scientists and clinical researchers. The *Roadmap's* plan to redesign clinical research also is consistent with the needs of severe mental illness research, calling for large clinical trials that engage not only multiple academic centers, but also providers in the real world and partnerships with other private entities, including the pharmaceutical industry, foundations, and consumer and family groups. Despite the correspondence between the needs for severe mental illness research and the NIH *Roadmap*, the Task Force fears that severe mental illnesses will be discriminated against in this bold initiative, even as these disorders are among the most applicable to the NIH's approach.

The Task Force emphatically urged significant increases in NIMH's funding which will be necessary to take advantage of the many research opportunities that exist for serious mental illness research. But the Task Force also noted that NIMH has not sufficiently prioritized severe mental illness research in its portfolio. One factor that inappropriately limits severe mental illness research funding at NIMH is the peer review process, which while being an optimal approach to assuring high quality research, fails to take into account the relevance of research to public health needs. To counter

this bias, the Task Force asserted that NIMH should expand the inclusion of public stakeholders, including consumers and family members, on peer review groups, among the panels that are not part of the larger peer review process managed by the NIH. It is also important that the *Roadmap* initiatives aimed at supporting the most creative and risky research ideas include severe mental illness research. And it is why methods for supporting research, such as NIMH

contracts, are essential, so that the public health agenda is adequately addressed. The leadership of NIMH and its council have the ultimate responsibility for shaping the research portfolio in a way that addresses the public health needs, the most compelling of which is severe mental illness. The Task Force calls for greater accountability on the part of NIMH in its investment of public funds for research.

Beyond the Rhetoric of Nature and Nurture—Depression Linked to Gene and Stress

One of the breakthroughs of 2003, touted by the premiere American scientific journal *Science*, was the report of a gene that doubles the risk of depression following stressful life events. Dr. Caspi and colleagues published a study in July of 2003 showing that nearly half of individuals who developed depression experienced both significant stressors in their lives and had a “stress-sensitive” version of the serotonin transporter gene. In contrast, only 17 percent of individuals with a different version of the gene, but significant stressors in their lives, became ill.

Serotonin is a neurotransmitter—a chemical that nerve cells use to communicate with one another—that has been linked to depression. In fact, the serotonin transporter, which is coded for by the gene identified in this study, is the target of widely used medications for depression. Previous studies, however, had been unable to link the gene to depression, because it is the combination of stressful life events and the “stress-sensitive” version of the serotonin transporter gene that predispose individuals to depression.

Not only does this study provide a specific example of how nature and nurture work together to produce a brain disorder, but it also provides scientists with potential new approaches to identifying individuals at increased risk of depression—and therefore who may especially benefit from preventive interventions—and for new approaches to drug development.

Caspi, A. et al., “Influence of Life Stress on Depression: Moderation by a Polymorphism in the 5-HTT Gene,” Science 301: 386, 2003.

Ultimately, as the panel discussion concluded, the entire system of care must be reformed, in line with the recommendations of the President's New Freedom Commission report. Fragmentation of policy and funding must be ended, and evidence-based interventions, the fruits of severe mental illness research, must be intimately integrated into the service system. Implementation of the Task Force's research recommendations, including large clinical trials and coordinated funding of health services research among various federal agencies, will significantly assist in this transformation. Better communication of the results of research relevant to practice on the part of NIMH and the Substance Abuse and Mental Health Services Administration (SAMHSA) is also needed. NIMH and SAMHSA must redouble their efforts to communicate clinically-relevant information to the public, through its website and various communications mechanisms. The Evidence-Based Practices Implementation Kits must be expeditiously and widely disseminated and other evidence-based practice guides developed. An essential part of reform of the mental health research and service system is improved communication on the part of the research agencies about treatment relevant findings. Finally, the creation of a federal entity that coordinates mental health service system policy and investment, so that it is consistent with research findings and provides feedback into the research priority-setting methods, would serve as an important mechanism for creating a seamless and science-based research and services system for individuals with severe mental illnesses of all ages.

Recommendations

The NAMI Research Task Force along with its Board of Directors is in strong agreement about the range of research opportunities that exist for serious mental illnesses, a research agenda that offers the promise of improvements in recovery for consumers today and significant gains in knowledge and treatments in the next ten years. They also agree that investment in research on severe mental illnesses, for individuals of all ages and ethnic/racial groups, must be significantly increased. The current state of our knowledge and interventions are inadequate, as is the implementation of effective treatments that exist. This underinvestment reflects inadequate funding of the NIMH, the principal federal agency charged with supporting severe mental illness research, insufficient prioritization of severe mental illness research at the NIMH and the NIH, and inadequate collaboration among federal agencies and other stakeholder institutions.

The Task Force concluded that simply increasing research funding for severe mental illness will not be sufficient for reaping the unprecedented promise for research and treatment advance. Resources must be accountably invested in the sophisticated approaches afforded by the post-genomic era of biomedicine, including modern molecular genetics and neuroscience, as well as large-population based epidemiologic studies and clinical research involving large networks of individuals and provider organizations in clinical and translational research trials, and health services research that results in the successful translation of new knowledge and interventions into practice and better outcomes for individuals with severe mental illnesses. Finally, the service system itself

must be better coordinated with the research enterprise.

Accordingly, the Task Force recommends the following:

1. A one billion dollar increase in NIMH funding over the next five years.
2. An increase in the percentage of NIMH's portfolio that goes to basic, clinical, and health services research relevant to severe mental illnesses, including children, adolescents, adults, older adults, and individuals from all ethnic and racial groups.
3. Investment in severe mental illness research that is in line with the current trends in biomedicine, including: basic neuroscience and molecular genetic studies that advance the basic understanding of the human brain and severe mental illnesses; research advancing the development of diagnostic methods and treatments; clinical and health services research that significantly increases its investment in large epidemiological studies, clinical research networks, and dissemination research.
4. A congressional directive for NIMH to prioritize severe mental illness research and for NIH to adequately address severe mental illness research in its initiatives, including *The Roadmap for Medical Research*.
5. An annual report from the NIMH to the U.S. Congress that clearly communicates the Institute's level and type of investments relevant to severe mental illnesses, describing investments according to the previous recommendations and research opportunities.
6. The NIMH expand its involvement of public stake-holders, including consumers and family members, in the peer review of proposals submitted to the NIMH, in order to insure that severe mental illness research is not only of the best technical quality but also is optimally useful to improving treatment of people with severe mental illnesses. NIMH should also increasingly use contract methods for research awards that are not adequately considered through the typical peer review channels.
7. The NIMH consider specific mechanisms for increasing the pool of researchers focused on severe mental illnesses, including the training of new investigators in the field of severe mental illness research, including student loan incentives, steering current researchers to the field, and the creation of research centers, especially in real world practice sites.
8. Increased application of research opportunities throughout the NIH for severe mental illnesses research, especially through the *Roadmap for Medical Research* funding initiatives, the National Child Study, and collaborations with other NIH institutes (e.g. National Institute on Drug Abuse, National Institute of Neurological Disorders and Stroke).
9. The NIMH and SAMHSA improve their public communication of research advances relevant to practice and consumer outcomes, including, but not limited to, the more expeditious development and dissemination of evidence-based practice implementation kits, and the improvement of the agencies' website so that they provide

more up-to-date and clinically relevant research-based information, as is the case with other NIH institutes. NIMH should also partner more with stakeholder groups, especially the National Association of State Mental Health Program Directors (NASMHPD), provider representatives, and consumer and family groups, to disseminate research findings.

10. Enhanced collaboration with other funding agencies in the federal government, including SAMHSA, the Agency for Healthcare and Research Quality (AHRQ), Centers for Medicare and Medicaid Services (CMS), Social Security Administration (SSA), U.S.

Department of Education (ED), U.S. Department of Veterans Affairs (VA), U.S. Department of Defense (DOD), and U.S. Department of Housing and Urban Development (HUD) in order to insure that all federal resources directed to severe mental illness research and services appropriately and efficiently implement and build on the current knowledge-base. To achieve this goal as well as the expeditious implementation of science-based interventions, NAMI calls for the creation of a federal body to coordinate and monitor federal severe mental illness research funding as well as the policy and financing of interventions and supports from the federal government.

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Appendix A: Research Task Force Members**NAMI Policy Research Institute's Task Force on Serious Mental Illness Research**

Edward M. Scolnick, M.D., President Emeritus of Merck Research Laboratories, and Ken Duckworth, M.D., NAMI's Medical Director, child psychiatrist, and former mental health department administrator, will co-chair the Task Force.

The executive committee of NAMI's Scientific Council, Jack Gorman, M.D., Chair of the Department of Psychiatry at Mount Sinai School of Medicine, Carol Tamminga, M.D., Professor of Psychiatry at the University of Texas Southwestern Medical Center, Robert Drake, M.D., Director of the New Hampshire-Dartmouth Psychiatric Research Center, and Kimberly Hoagwood, Ph.D., Professor of Clinical Psychology and Psychiatry at Columbia University, New York State Psychiatric Institute will serve as the coordinating members of the Task Force.

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