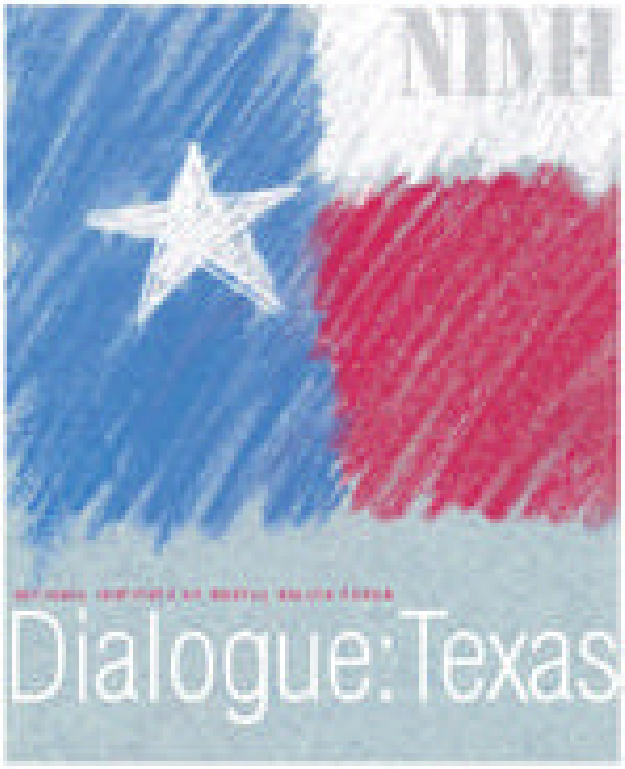

DIALOGUE: TEXAS

MENTAL HEALTH RESEARCH PLANNING FORUM

December 8, 1999

San Antonio, Texas

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I. INTRODUCTION

"We're here to listen."
Dr. Steven E. Hyman, Director of NIMH

On December 8, 1999, the National Institute of Mental Health (NIMH), the Federal agency responsible for the Nation's mental health research, held a trail blazing mental health forum in San Antonio, Texas. The forum, DIALOGUE: TEXAS, was the first in a planned series of regional meetings to seek input from members of the public on shaping the Institute's future research activities. Texas was selected as the first site because it has a solid core of mental health researchers and consumer and advocacy organizations. Moreover, Texas is a state rich in cultural diversity.

NIMH worked closely with consumer and professional organizations, universities, and State and local agencies to plan DIALOGUE: TEXAS and to promote an open sharing of ideas and expertise. Individuals with mental disorders, their family members, care providers, as well as policymakers and researchers, were invited to help set NIMH's research priorities. The forum proved to be a major success, generating key ideas and questions that will inform NIMH's research priorities, enhancing that research's relevance and responsiveness to America's mental health needs.

A. NIMH's Mission

"*NIH should more fully engage the public--that is, the public should have greater opportunity to learn about and provide input into the process by which NIH sets its research priorities--in a process that is led by the NIH director, guided by reasonable criteria, and well informed by robust analyses of health statistics."*

Improving Priority Setting and Public Input at the National Institutes of Health
Scientific Opportunities and Public Needs:
Improving Priority Setting at the National Institutes of Health
Institute of Medicine

The mission of NIMH is to diminish the burden of mental illness through research. This public health mandate demands that the Institute harness powerful scientific tools to achieve better understanding, treatment and, eventually, prevention of mental illness.

Research in basic neuroscience, behavioral science, and genetics helps researchers gain an understanding of the fundamental mechanisms underlying thought, emotion, and behavior, as well as an understanding of what goes wrong in the brain in mental illness. In itself, this information will provide profound insights into human beings as a species. At the same time, NIMH must hasten the translation of this basic knowledge into clinical research that will lead to better treatments. These treatments ultimately must be effective in a complex world with diverse populations and evolving health care systems.

The stakes for America are high. According to the landmark "Global Burden of Disease" study, commissioned by the World Health Organization and the World Bank, mental disorders represent four of the ten leading causes of disability for persons age 5 and older. Among "developed" nations, including the United States, major depression is the leading cause of disability. Also near the top of these rankings are manic-depressive illness, schizophrenia, and obsessive-compulsive disorder. Mental disorders also are tragic contributors to mortality, with suicide perennially representing one of the leading preventable causes of death in the United States and worldwide.

Fortunately, research has yielded effective treatments for many mental disorders; however, successes to date are far from complete. As is true of treatments for most serious chronic illnesses that afflict humanity, current treatments for mental disorders control symptoms but do not cure the disorder. The tragedy of mental illness demands that as a society we respond to it effectively, ethically, compassionately, and together.

B. Stakeholder Input

To move research forward and to hasten the progress from basic knowledge to effective treatment, one of NIMH's most important current priorities is to increase public participation in planning and setting

priorities. This priority is one aspect of NIMH's long-time commitment to be responsive to its stakeholders, while also responding to input from Congress and prestigious scientific advisory bodies.

Congress, for example, has asked how the budget increases it has recently provided the National Institutes of Health (NIH) will affect priority setting. In addition, a recent report by the Institute of Medicine (IOM) Committee on the NIH Research Priority-Setting Process concludes that, "NIH's system for setting priorities has generally served NIH and the nation well in supporting research to improve human health, but some changes would strengthen it, especially in mechanisms for exchanging information and concerns with interested individuals and groups." In particular, the report notes that NIH should give the public greater opportunity to provide input into NIH's research priorities.

In his formal message to DIALOGUE: TEXAS, Dr. Steven E. Hyman, Director of NIMH, noted that NIMH is one of the few institutes to invite public participation on its grant review committees, and is broadening the range of perspectives brought to the review of grant applications for treatment and services research. "Specifically," Hyman said, " we have invited persons who have had personal experience with mental disorders—as patients, family members, service providers, policymakers or educators—to apply to become members of review committees."

NIMH is committed to doing even more. Basic and clinical research has improved understanding and treatment of mental illness, and will eventually prevent it. Nevertheless, in recent years, the majority of Americans who could benefit from care still fail to get treatment. DIALOGUE: TEXAS is part of NIMH's ongoing effort to help people understand what has been learned about what goes wrong in the brain in mental illness, to inform them about new treatments, and to gain insight into what the consumers of research think is needed

In describing why NIMH held its Mental Health Forum in Texas, Dr. Hyman said, "We're here to listen. By talking directly with the people, NIMH can gain a tremendous amount of valuable information that can enrich its research plans for the coming years."

C. The Strategic Plan

DIALOGUE: TEXAS took place while NIMH was developing its Strategic Plan for Brain and Behavioral Research (http://www.nimh.nih.gov/strategic/strategicplan.htm#draft, posted June 21, 1999) in the new millennium. One of the major purposes of the forum was to provide information that could be used in the strategic planning process.

The three broad primary goals outlined in the strategic plan are: (I) Understanding Mental Illness; (2) Understanding How to Treat and Prevent Mental Illness; and (3) Assuring an Adequate National Capacity for Research and Dissemination.

II. THE MENTAL HEALTH CHALLENGE IN TEXAS AND THE NATION

Texas Congressmen Ciro D. Rodriguez and Charles A. Gonzalez opened the forum by offering perspectives on the mental health challenges faced both by Texas and the nation.

In his presentation, Representative Rodriguez stressed several key points:

- Mental illness is a serious public health challenge that impacts millions of people, but is still very under-treated.
- The reasons for undertreatment include a lack of facilities and service, as well as a lack of proactive treatment.
- The Congressional Hispanic Caucus sponsored Hispanic Health Awareness Week and held hearings on a variety of issues, including the links between mental health and substance abuse.
- While NIMH should continue to follow its research agenda, it should also examine how services are being provided and ensure that the results of research reach the populations that need them most.

He concluded by pledging to work for legislation that would target greater resources on the mental health needs of Hispanics and other ethnic populations who were suffering from mental illness.

In his remarks, Representative Gonzalez noted:

- Mental illnesses—especially-depression and stress—are an increasingly pressing health problem.

- One of the most important factors responsible for stress and depression is the stress on the modern American family: divorce, working families, and blended families.
- Most schools lack sufficient mental health professionals trained to deal with the many challenges children face.
- Stress is also a result of the fact that Americans are working longer and harder.
- Millions of Americans lack medical insurance, which means they cannot afford a visit to a mental health professional.
- In dealing with these issues, the government has a major role to play, especially in establishing a high standard for service.

He concluded by calling on the mental health community to make their demands for more funding and more services known to Congress.

III. THE ROLE OF STAKEHOLDERS IN NIMH RESEARCH

Dr. Steven E. Hyman introduced the session on Research Capsules by providing an overview of research at the Institute and by stressing NIMH's commitment to encouraging input by stakeholders into research priorities. He noted that 83% of NIMH's research budget is spent on extramural research conducted at facilities across the country; 13% is spent on intramural research; and 4% is spent on research management support. Some 75% of the applications for extramural research support are not funded, he said.

NIMH's major research areas include:

- Basic behavioral and neuroscience research
- Depression
- Schizophrenia
- Anxiety disorders
- Attention-deficit/hyperactivity disorder
- Autism
- Rural mental health
- Child and adolescent violence

- NIMH human genetic initiative
- Human brain project
- Prevention research initiative

NIMH also funds studies in the areas of eating disorders, conduct disorder, learning disorders, personality disorders, Alzheimer's disease and related dementia, sleep disorders, brain effects of HIV/AIDS and behavioral methods of reducing the spread of the virus; the prevalence of and risk factors for mental disorders; mental health problems of special populations; and mental health services research, including mental health economics and improved methods of services delivery. Dr. Hyman emphasized that NIMH's research program is flexible enough to allow adjustments to meet new needs as NIMH launches special research programs to deal with emerging needs. For example, in the last four years NIMH recognized that there was not enough information available about how psychotropic drugs could best be used to treat mental disorders, so it launched a special research program on that issue.

Hyman also stressed that NIMH is dedicated to stakeholder involvement in setting research priorities. He described the many opportunities that the investigator community, NIMH constituency groups, and The public has to provide advice and input on NIMH research. "You can actually influence the kinds of applications we get from scientists, by letting them know *this* is what we need, *this* is what NIMH should be looking at." The mental health community can also recommend NIMH set aside specific funds to meet a particular need or advise NIMH to hold conferences or workshops on unmet needs.

He added that DIALOGUE: TEXAS is one of a number of attempts NIMH is making to increase the input of the interested public into priority setting. "In addition to telling us about what research is needed," he said, "tell us about how we can improve our efforts—how we can not seem like a distant agency in Washington, but be a better partner."

Dr. A. John Rush, M.D., a member of the National Advisory Mental Health Council, presented following Dr. Hyman. Dr. Rush is Professor, Betty Jo Hay Distinguished Chair, Department of Psychiatry Southwestern Medical Center, University of Texas in Dallas, Texas. He also chaired the Advisory Council's Clinical Treatment and Services Research Workgroup, which conducted

a thorough reappraisal of the manner in which NIMH explores and evaluates clinical innovations and moves them into the hands of service providers.

Under Dr. Rush's leadership, a core group of the Nation's most distinguished treatment and services researchers met over the course of a year, among themselves, with outside consultants, and with members of the NIMH and other Federal officials. They produced a report, "Bridging Science and Service" (http://www.nimh.nih.gov/research/bridge.htm) that advises the Council on strategies for increasing the relevance, speeding the development, and facilitating the utilization of research-based treatment and service interventions for mental illnesses into both routine clinical practice and policies guiding our local and national mental health service systems.

In discussing the report, Dr. Rush stressed that one of the keys to successful research was to involve the people who use mental health research in developing the research agenda. He identified mental health research stakeholders as:

- Patients and their families
- Clinicians
- Health care administrators
- Policymakers, purchasers, and insurers
- Researchers

Dr. Rush identified several key assumptions of the Bridge report:

- Research findings are often not implemented.
- Participation by end users in developing research priorities will increase both the relevance of research findings and the likelihood that they will be implemented.
- Diverse mental health stakeholders have different but overlapping priorities.
- Research ultimately serves patients first; the acquisition of research knowledge is a "process" variable.
- No research will be adopted by care systems without cost estimates.

Dr. Rush then presented four research domains that encompass treatment and services research as defined by the Bridge report. These include:

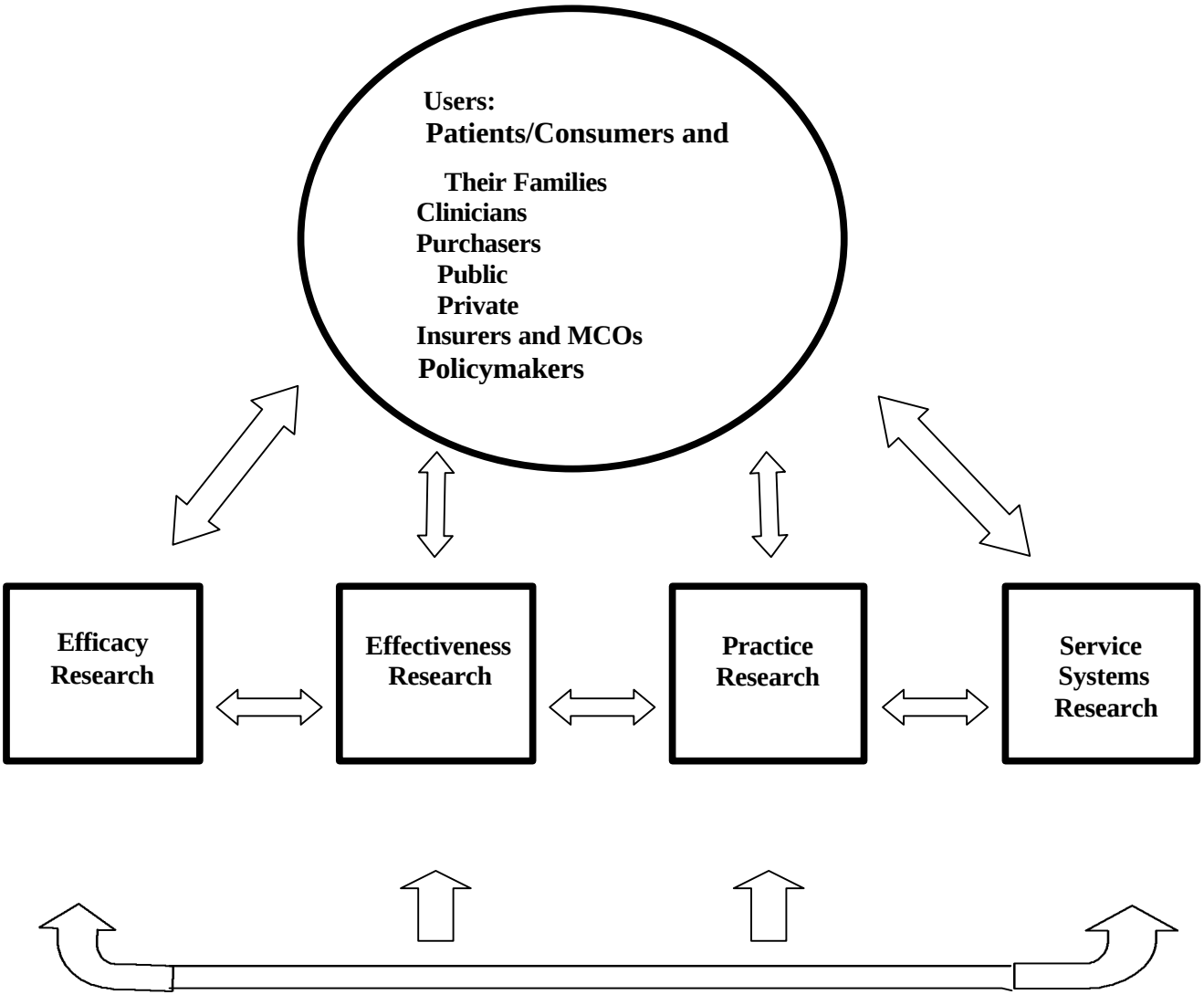
- *Efficacy Research*—The purpose of efficacy research is to examine whether a particular intervention has a specific, measurable effect and also to address questions concerning the safety, feasibility, side effects, and appropriate dose levels. As a consequence, the classic efficacy study is a clinical trial in which an experimental treatment is compared to a control treatment that can be a standard treatment and/or a placebo.
- *Effectiveness Research*—The principal aim of effectiveness research is to identify whether efficacious treatments can have a measurable, beneficial effect when implemented across broad populations and in representative service settings. For instance, any person seeking help with a particular mental illness, regardless of other co-occurring conditions or the duration of the illness, might be eligible. Treatments are administered by clinicians who have not necessarily been specially trained in the research protocol; patients/consumers and clinicians exercise choices over treatments; and the frequency and duration of visits, how and when outcomes are gauged, and the use of adjunctive services are dictated by local practice patterns or administrative policies.
- *Practice Research*—Practice research examines how and which treatments or services are provided to individuals within service systems, and evaluates how to improve treatment or service delivery. The aim is not so much to isolate or generalize the effect of an intervention, but to examine variations in care and ways to disseminate and implement research-based treatments. Although some studies may have randomized designs, currently most are observational.
- *Service Systems Research*—Service systems research addresses large-scale organizational, financing, and policy questions. This includes the cost of various care options to an entire system; the use of incentives to promote optimal access to care; the effect of legislation, regulation, and other public policies on the organization and delivery of services; and the effect that changes in a system (e.g., cost-shifting) have on the delivery of services.

"Each of these domains has to talk to each other," Dr. Rush said. He reported that in an effort to bridge the existing divisions between the domains, the Workgroup developed a model that took into account these four types of research and the potential users of research (i.e., patients/consumers and families, clinicians, public and private purchasers, insurers and HMOs,

and policymakers). This model (see Figure 1) demonstrates the interconnectedness of these domains, which are commonly, but inappropriately, viewed as discrete or linear.

Figure 1

Relationships Among Research Domains and Users of Findings



Dr. Rush also discussed with the Forum the Workgroup's assumptions related to the research domains.

- Efficacy (knowing it works in a research setting) is the beginning.
- Implementation (using it in a natural setting) is the end.
- Each domain should anticipate what the others need to know (e.g., efficacy researchers should estimate cost of implementing.)

Dr. Rush then turned to priority setting. He noted that the overall aim of research priority setting was improved mental health. Priorities also have to be governed by scientific opportunities, he said, especially by the answers to two key questions:

- What can science measure?
- What questions are ripe for study?

Within these parameters, research priorities should be set by NIMH's stakeholders: Patients and their families; Clinicians; Purchasers; Policymakers; Insurers; and Researchers.

Dr. Rush concluded his discussion of the Bridge report by outlining some of its key recommendations:

- Research priority setting should include all stakeholders, not just researchers.
- NIMH should synthesize and disseminate what is known in intervention research.
- NIMH should create an infrastructure to monitor public/mental health, including the development of mental health indicators that would function like economic indicators.

Dr. Rush stressed that NIMH listens very carefully to input on research priorities from many different sources: Congress, the National Advisory Mental Health Council, etc. One of the most important inputs, however, is from stakeholders. "This is the first time NIMH has come to the grassroots to ask what our priorities should be. Our task is to improve outcomes for people with mental illness."

IV. RESEARCH CAPSULES:

At "Research Capsules," a two-hour Forum session on December 8, NIMH researchers and NIMH staff gave presentations designed to help attendees learn more about the institute's cutting edge research for the coming decade.

"The capsules give a snapshot of what's exciting in mental health research today," said moderator Dr. William Vega, Professor and Director of Metropolitan Research and Policy Institute at The University of Texas, San Antonio. Dr. Vega emphasized the need for communication between the research community on the one hand and practitioners and consumers on the other. "It is very clear," he said, "that there is a gap between the level at which research is formulated and conducted, and the level at which services are actually delivered. The key question we face today is how to translate the current agenda of research to improve our capabilities so we can have a more effective course of treatment for people operating in the field and for people and families suffering from psychological disorders. How can we produce better results at reduced cost?"

A. Creating Advances in Treatment

Dr. Matthew Rudorfer, Assistant Chief of the Adult and Geriatric Treatment and Preventive Intervention Research Branch at NIMH's Division of Services and Intervention Research, said that optimism about mental health in recent years has been fueled by new interventions, many of them generated by NIMH research on developing new treatments and approaches to mental illness. He told forum attendees that NIMH has been complementing short-term efficacy trials with longer-term effectiveness research, which is more and more based on a public health model. Such effectiveness research features:

- A diversity of patients, more like those seen in an actual clinical practice than in a typical clinical trial
- Varied settings beyond the hospital environments of many clinical trials
- A range of clinicians
- Broad outcome measures that include functioning as well as symptoms

Dr. Rudorfer noted that as part of its increased use of the public health model in research, NIMH has launched a new research project on bipolar disorder. Although depression is one of the phases of bipolar disorder, people with bipolar disorder have been routinely excluded from the efficacy trials needed to bring antidepressant drugs to market in order to test the drugs on a select population.

To provide more data on treating bipolar disorder, NIMH recently launched the Systematic Treatment Enhancement Program for Bipolar Disorder. The special challenges of treating bipolar depressed patients will be studied among 5000 patients at 20 sites around the country including two in Texas.

In elaborating on NIMH's new approach to research, Dr. Rudorfer noted that most efficacy trials have traditionally focused on the acute treatment response to episodes of depression. "While this is important," he said, "acute treatment research is not a sufficient response to a disorder that requires long-term intervention due to the risk of relapse and recurrence."

To illustrate, Dr. Rudorfer described some new NIMH research that is helping to illuminate some of the uncharted areas of chronic care for depression. Dr. Rudorfer cited a study at the University of Pittsburgh of geriatric patients who had responded well to treatments for acute depression. The study tested a range of treatments to determine which ones worked best at helping patients stay well for an extended period—three years. The study found that those patients treated with a combination of antidepressant medication and interpersonal psychotherapy were most likely to remain free of additional episodes of depression. The study, Dr. Rudorfer said, provides researchers with more information about what are the best interventions to treat a key illness over time. In addition, the study helped establish questions for further research and established a standard against which other studies could be compared. Finally, he said, the study shows that depression is not simply a normal part of aging. It is a disorder for which research has provided effective treatments for today and hope for tomorrow.

Dr. Alec Miller, Director of the Division of Schizophrenia and Related Disorders at The University of Texas Health Science Center at San Antonio, next presented some recent research on schizophrenia. Dr. Miller described his work as “in-the-trenches” research where “we try to do things that have direct applicability that can be translated into practical mental health care.”

Dr. Miller noted that is has long been known that schizophrenia has multiple components: both positive symptoms (hearing voices, delusions, etc.) and negative symptoms (lack of motivation, lack of emotional involvement, diminished thought production, cognitive deficits over a wider spectrum, etc.). However, only recently have researchers discovered the impact of negative symptoms on how well patients function.

“The bottom line,” Dr. Miller said, “is that if you look at the contributions to impaired functioning in people with schizophrenia, positive symptoms are the least influential factor. They don’t correlate highly with impairment of functioning.” On the other hand, negative symptoms do have a strong negative impact on functioning, Dr. Miller said. “The clear conclusions,” he added, “is that if you want to improve functioning, your treatment should have an impact on negative symptoms and cognitive deficits.” In fact, Dr. Miller’s research has shown that cognitive deficits are the preeminent contributor to impaired functioning in people with schizophrenia.

Dr. Miller then described a recent research project, Cognitive Adaptation Training (CAT). In the project, therapists used interventions that included going into patients’ living environments and using very practical interventions (calendars, checklists, training) to promote desired behaviors and decreased undesirable ones. The strategies for treatment are based on cognitive testing of the patients. Thus far, Dr. Miller reported, patients who have undergone the CAT training have improved their self-care skills, their social skills, and their role functioning. Dr. Miller emphasized that further study is needed, but initial results were quite positive.

Studies such as CAT, he said, show that clinical care can be improved by using evidence based tools, but these tools must be compatible with clinical realities.

SIDEBAR

Bringing Research into the Real World–Two New Studies

Proof of effectiveness under "real world" conditions will be the aim of two large-scale clinical trials funded by NIMH. One will identify which new generation antipsychotic medications–used to treat psychosis in schizophrenia and behavior problems in Alzheimer's disease–are best for which patients. A second set of trials will investigate how to help people who have not responded adequately to existing talk and drug therapies for depression.

A research team headed by Jeffrey Lieberman, M.D., University of North Carolina, has been awarded a contract to conduct the trials of antipsychotics over 5 years. Another team, headed by A. John Rush, M.D., The University of Texas Southwestern Medical Center, and colleagues, were awarded a contract to conduct the trials on treatment refractory depression, also over 5 years. The Institute is investing a total of more than $100 million in four such new large-scale trials; similar trials on treatment of adolescent depression and manic-depressive illness were also funded over the past year.

"Unlike the smaller, more narrowly focused studies of the past, these new trials will be based on a broader public health model of intervention," explained NIMH Director Steven E. Hyman, M.D. "We will examine what treatments work on diverse individuals in real world settings–not just rarified research clinics. In addition to studying the effectiveness of the treatment, we plan to gain important information on cost-effectiveness and patient adherence to treatment."

For example, to minimize potentially confounding factors, previous treatment studies of depression usually excluded potential study participants if they had a co-existing medical illness such as heart disease, a co-occurring mental illness, such as an anxiety disorders, or a co-occurring drug or alcohol problem. Such trials were informative, but were not generalizable to a vast number of individuals with depression. The new trials will enroll such patients precisely because co-existence of more than one illness is common, if not the rule, in the real world. Similarly, past studies tended to test a particular treatment in a single setting, most often a clinic at an academic health center. The new trials will strive for demographic and geographic diversity in multiple clinical settings so that the findings will have broad applicability.

An additional difference between conventional efficacy trials and the current NIMH sponsored trials is that the new trials will be of longer duration and will not only measure symptom reduction, but also functional status, including levels of disability.

"These are the issues that have the most practical relevance for patients and mental health caregivers," noted Hyman.

The new NIMH-supported trials of the new antipsychotics will develop a network of sites and investigators able to respond to future needs for treatment research. The studies in schizophrenia, involving 1000 patients, will gauge how the drugs affect long-term outcome, including cognition, mood, suicidality, interpersonal interactions, vocational achievement, and quality of life. For Alzheimer's disease, the trials, involving 500 patients, will attempt to define which symptoms and behaviors are appropriately treated with the new drugs, as well as safety and long-term outcome issues. Trials of treatments for refractory depression will be conducted in a wide range of clinical practice settings to determine the long-term effects of different sequences of drug and psychotherapy treatments. Patient recruitment for the trials is expected to begin in Fall 2000.

B. Children's Mental Health Needs

Dr. Kimberly Hoagwood, Chair of the NIMH Child Consortium and Associate Director for Child and Adolescent Research, began by saying she would frame her discussion of NIMH's research on children's mental health around two themes. First, while there has been a tremendous amount of knowledge growth, especially in the Goal 1 areas–understanding the needs of children, treatments, and services–more must be done to make this knowledge usable. Second, science often progresses by replacement. "Sometimes we have to be prepared to ditch treatments if they're not working," she said.

She then described the "phase model" NIMH tries to use in its research on children's mental health. The phases include:

- Development of new interventions, treatments, or services
- Outcome trials–testing the efficacy and impact of treatments
- Sensitivity studies–testing an intervention with different populations

- Specification studies-- looking at specific doses and durations of treatment that are most effective
- Cost-Effectiveness studies

She noted that some of these phases can be combined in major clinical trials.

Dr. Hoagwood also reported on a brief analysis she did on the current status of clinical trials of the 16 most common mental health services provided to children. Her analysis yielded information o the utility of these trials in treating and preventing mental illness. "The evidence we have is very spotty. There are a lot of services being used for which we have no evidence."

Dr. Hoagwood then noted some of the problems NIMH has in matching effectiveness research on children's mental health to policy:

- Research lags behind policy.
- There is a lack of systematic and critical synthesis of what has been studied.
- It is difficult to prevent the problem of poor evidence from accumulating.
- Unstudied services are still being delivered.
- The evidence base remains spotty.
- Practice is not informed by research.

Dr. Hoagwood then introduced Dr. Graham Emslie, Professor of Psychiatry at University of Texas - Southwestern Medical Center, who discussed his pioneering research on depression in children and adolescents.

Dr. Emslie began by reviewing how research has helped improve the understanding of child and adolescent depression. He pointed out that it is now clear that the treatment of children at an early age is important, and that if child and adolescent depression is untreated, the risk of suicide increases. Suicide, he noted, has become the second leading cause of death among adolescents.

Dr. Emslie also said that the epidemiology of depression in young people is generally similar to that of adults, but with some important differences. Interestingly, depression occurs as often in

male children as among female children, but the ratio changes in adolescence, with twice as many females as males being affected. He added that diagnosis can be a challenge because young people often don't "look depressed," in the same way as adults.

In discussing how to treat and prevent depression in children and adolescents, he noted that a 1997 NIMH-funded study published in the Archives of General Psychiatry, on which Dr. Emslie was the lead researcher, that supported an SSRI anti-depressant as a safe and efficacious medication for child and adolescent depression. Other complementary clinical studies are beginning to report similar positive findings in depressed young people treated with several newer antidepressants. However, Dr. Emslie noted that much research remains to be done on the use of antidepressants with children. "Until recently there was little interest in studying medications for kids," he said. "It was just assumed you could extrapolate the results from adults to children and adolescents. But there may be developmental differences that lead to a difference in response."

Dr. Emslie then listed areas where further research work is needed, including:

- Remission following treatment
- How long to continue treatment
- Use of Cognitive Therapy

Dr. Emslie offered several general conclusions from current research:

- Depression is under-recognized and under-treated.
- Some antidepressant drugs appear to be a safe and effective treatment.
- The majority of patients recover within 6 months.
- Some 10-20% of patients are treatment resistant.
- Recurrence is common.
- Compliance with drug treatments still needs to be studied.

"Kids think they're cured only if they stop taking drugs," Dr. Emslie said in explaining the last point.

In the discussion period that followed the Hoagwood and Emslie presentations, questioners asked about the links between depression and other conditions such as reading disorders. Dr. Emslie answered that one would need to weigh many different individual factors, and each patient needs careful evaluation. However, he said, it is true that children can have clusters of mental health issues.

Other forum participants asked questions on family-driven care. Dr. Hoagwood said involving families in research gives researchers important insights on issues such as what kind of treatment and side-effects are acceptable for the child, the optimal places where the care can be provided, and the kinds of research answers that will ultimately be most meaningful to families.

C. Preventing Violence

Dr. Farris Tuma, Chief of the Traumatic Stress Program and Disruptive Behavior and Attention Deficit Disorder at NIMH's Division of Mental Disorders, Behavioral Research and AIDS, noted that work on violence is an area of long-standing interest to NIMH, with research on understanding violence and understanding how to treat and prevent it, going back decades. "Our work has helped us understand what places people are at risk for violence, as well as providing interventions and ways to treat conditions that result from being exposed to violence," he said.

In particular, NIMH work has focused on several areas of interest, including:

- Abuse and neglect of children
- Inter-partner violence
- Large-scale trauma and violence, including research with veterans, people exposed to disasters, and people exposed to large-scale violent events, such as school shootings.

In research on victims and survivors of trauma, Dr. Tuma said, much of what has been learned comes from work with survivors of disasters. "The goals of this research are fairly simple," he said. "We want to understand who is at highest risk for developing mental health problems and conditions. We are focusing on understanding the consequences of exposure and traumatization and approaches to intervention."

This research has been useful in developing interventions that can help those people at highest risk of suffering from exposure to violence. While we have made progress in treating the mental health consequences of trauma, including PTSD, a challenge remains to find ways to identify those people who are at the highest risk due to exposure to violence and develop ways of preventing mental health problems.

Dr. Tuma then turned to NIMH research on children and adolescents who commit violence. Research on aggression and violent behavior in children, he said, has focused on identifying the external behavior problems in children that place them at risk for violent behavior later in life. Much research has focused on questions such as: What are the risk factors for children, especially as they pass through key points in their lives? What might protect them from becoming aggressive, and potentially violent individuals?

He reported to the forum that, the *good news* is that three to four decades of research had developed a handful of effective interventions to prevent early behavioral problems and/ or reduce violent behavior in children who are already engaging in it. However, he noted that we have very little research on the emotional disorders linked to many of the problems of violence–such as depression in children–that coupled with impulsivity can be important predictors of who is likely to engage in aggressive and violent behavior.

He also reported some *not so good news*: the majority of the prevention programs now in place in schools and elsewhere have not gone through a rigorous process of testing to determine whether they are effective. "Moreover, they have not even been tested to see if they make the problems worse," Dr. Tuma said. He concluded by emphasizing that one of NIMH's biggest problems is how to take the research that has been done and move it into communities.
Dr. Edward Mulvey, Professor of Psychiatry at the University of Pittsburgh's Western Psychiatric Institute and Clinic described some current NIMH-funded research aimed at understanding mental illness. In particular, the research examines the link between mental illness and violence.

Dr. Mulvey said that analyzing whether there is a link between illness and violence, and determining what that link might be, will continue to be an important research question as we enter the next millennium, for several reasons. First, it is an age-old question that society has tried to understand for hundreds of years. In addition, the question is embedded in our popular culture. Second, it is part of clinical practice. Mental health professionals will continue to be called upon to assist public officials about how to deal with violent individuals with mental illness.

He reported that epidemiological evidence suggests there is a link between diagnosis of mental illness and violence. However, the association is very modest, a correlation of only .2. He added that only a small part of violence in our society (perhaps 5 to 10%) is attributable to individuals with mental illness. Active symptoms are more important than diagnosis, and drugs and alcohol play a major role.

Dr. Mulvey then turned to the question: can mental health professionals predict future violence? Mulvey presented findings indicating that clinicians can make such a prediction more accurately with some people than others. For example, clinicians can make more accurate predictions about male patients than with women. He also noted that using models based on risk factors results in more accurate predictions than do clinical judgments alone.

Dr. Mulvey then turned to a more specific question that has been much in the news because the recent spate of school shootings: can we identify adolescents who will be violent? Unfortunately, Dr. Mulvey said, it's particularly difficult to make such predictions in adolescents.

Dr. Mulvey concluded by offering some suggestions for future research on the links between violence and mental illness. Researchers will try to develop more refined approaches to the problem. He also reported that research will give added emphasis to ongoing assessments of changes in risk state than to overall risk status.

D. Mental Health Research and Cultural Diversity

Dr. Junius Gonzales, Chief of the Services Research and Clinical Epidemiology Branch at NIMH's Division of Services and Intervention Research, began by saying that within NIMH's research portfolio, there has been a long-standing interest in research on cultural diversity. He noted that within his branch at NIMH, there is a specific program, the Social-Cultural Program, that supports research focuses on issues of culture, ethnicity, and social networks.

During the fiscal year 1999, Dr. Gonzales's branch had 14 grants that focused on Latino populations. Dr. Gonzales then highlighted some of this ongoing research. Dr. Leticia Lantican, Director of the School of Nursing at the College of Health Sciences at The University of Texas at El Paso, has a grant to study people with mental health problems in primary health care settings. Dr. Gonzales' branch also funds a study by researchers in Puerto Rico. The Puerto Rican research center is coordinating five partner sites examining the differences and similarities within Latino groups throughout the United States. Center researchers are trying to answer a range of questions including:

- How do we adapt treatment instruments to different Latino populations?
- How can established interventions be used for diverse Latino groups?

Another NIMH grantee, a large social work center at Fordham University, is focusing on a number of important subpopulations within the Latino population, especially within the New York area. These subpopulations include depressed elderly and depressed young women who are pregnant. The goal is to develop culturally relevant and applicable interventions for those populations.

NIMH is also funding the work of Jeanne Miranda, Ph.D, Associate Professor, Department of Psychiatry, Georgetown University Medical School, who is doing a large study on African American and Latino women who are being treated in family planning programs. Dr. Gonzales was involved in this program while he was at Georgetown University. The project found that the two populations had very different reactions to the treatments being tested: medication and cognitive/behavioral therapy in a group format. Latino women were very much against group

therapy, so researchers had to implement an education program prior to that intervention. African American women, on the other hand, were very much against medication. Thus, the program had to educate them about that intervention.

Dr. Gonzales discussed another research project in which the encounters between Latino women and service providers were videotaped over time. Researchers then worked with anthropologists to try to determine what explanatory model the patients and the caregivers were using. The hypothesis being tested is that the best outcomes occur when the patients' explanatory model of behavior converges with the providers' explanatory model.

SIDEBAR

A Bi-Cultural Approach in San Antonio

"Imagine the shock of a Mexican-American with a mental illness who is in a Texas hospital where no one speaks his language. When that same patient comes to us, he says to himself, 'Oh, I am with my people.' The patient can relax, and then focus more on recovery, not on communicating through a language barrier."

--Janette Rodriguez, San Antonio State Hospital- Houston Hall Bi-Cultural Unit

As a staff psychologist at Houston Hall Bi-Cultural Unit, Janette Rodriguez came to the San Antonio NIMH Forum to learn more about the trends in mental illness research and its impact on her patients, but she left the conference and its participants with a better idea on how to treat a special population of consumers.

Part of the state hospital system, Houston Hall Bi-Cultural Unit in the San Antonio State Hospital, is a specialty unit dedicated to the treatment of Spanish-speaking, patients with mental illness, between the ages of 18 and 64. The only unit of its kind in Texas, Houston Hall began in 1968 under a Hospital Improvement Grant of four years to provide for Mexican and Spanish-speaking patients with chronic schizophrenia. After the grant was completed in 1972, the unit expanded its treatment beyond schizophrenia to include other mental illnesses. With a forty bed capacity, Houston Hall has experienced more growth in the last five years to allow for longer treatment periods, which can be anywhere between 1 year to the rest of a patient's life.

Under the leadership of Myrna Tucker, M.D. and the unit director, Santos Vargas, L.M.S.W., Houston Hall offers Spanish-speaking patients a more holistic approach to treatment. The structure of the unit encourages the inclusion of the patient's family, cultural enrichment and an accessible staff. Rodriguez explained that Houston Hall "focuses on the cultural needs of patients. This means incorporating Mexican and Hispanic cultures…For example, we just celebrated *La Virgen de Guadalupe* on December 13th. This is a huge, huge, feast day in Mexico. For us, it wasn't just a party. We studied the origins of feast day and its greater significance to the society. The patients' family members helped out too. We then created a skit about the feast day and invited the hospital-at-large. It was a great opportunity for the patients to learn about their culture." She went on to say that Houston Hall's greatest accomplishment was making a difference in the patients' lives, because "language is the primary way people communicate to one another. A shared language means better services."

The emphasis on education also ensures better services. To this end, Houston Hall has helped coordinate over the last six years a bilingual conference called "South Texas Family Support Conference." Its mission is to reach out to the communities in the southern Texas region through a conference held in both languages, and provide continuing education for consumers and their family members. This year, the conference is scheduled for June 1-3 in Victoria, Texas, and next year's conference in 2001 is set for Austin, Texas. There are over 400 participants, primary family members and consumers who attend this annual conference.

Rodriguez said that the NIMH San Antonio Forum was a great learning experience, because "the speakers were very accessible, and the participants seemed to really get a lot out of the sessions." She pointed specifically to the Breakout Group: Talking about Mental Illness and Stigma. "It helped both consumers and professionals to listen to each other. Much of the stigma of mental illness comes down to semantics." On the topic of potential NIMH research funding, Rodriguez would like to see some research on the interaction between diet and the effectiveness of mental illness medication. The difference in diet, even among the Spanish-speaking communities in the United States, from Florida, the Midwest, California to Texas, appears to have huge implications in the efficacy of some medications and treatments." After the San Antonio NIMH Forum, Houston Hall's reputation as place for specialized treatment for minority populations, in this case Spanish-speaking patients, has spread well beyond southeastern Texas.

Dr. Javier Escobar, Professor and Chairman of the Department of Psychiatry at the University of Medicine and Dentistry of New Jersey, reported some key research on cultural diversity. He began by noting that he had recently become a member of NIMH's Mental Health Council, and said he hoped to use input from the Texas Forum in the recommendations he makes while serving on Council.

"I want to start with the bottom line," he said. "There is very little knowledge beyond epidemiology about the mental health risks and protective factors for Mexican-Americans." He added, "We are years behind mainstream psychiatry in knowing how treatments work in our populations. We need to modify and adapt treatments. We also need to increase the number of Hispanics doing research, and we need to increase the number of research projects on Hispanics."

The key questions in research on the mental health needs of Mexican American, he said, are:

- Why do immigrants seem to have better mental health outcomes than non-immigrants?
- Why are rates of uses of mental health services lower for Mexican Americans than for other groups?
- How can we improve outcomes and develop better interventions?

Turning first to under-utilization of services, Dr. Escobar reviewed data that showed not all Hispanics underutilize services. Mexican Americans lag behind Puerto Ricans, and Cubans in use of services, for example, as well as behind African Americans and Caucasians. We don't know why this is so, Escobar said, but we do have some important hints. It does seem to help improve service utilization rates when service providers have staff who can speak Spanish, and have knowledge of Mexican American culture. In addition, Escobar said, we need to increase the percentage of Mexican Americans on medical school faculties and increase the number of residents in psychiatry.

Escobar then moved on to one of the curious findings in research on Mexican Americans: Mexican American immigrants seem to have better mental health outcomes than other groups,

and recent immigrants seem to have better mental health than Mexican American who have been born in the United States.

Dr. Escobar cited work by Dr. William Vega showing that in Fresno, California, Mexican Americans born in the United States have a much higher incidence of mental disorders that do Mexican Americans born in Mexico.

Dr. Escobar concluded by stressing that these mental health advantages of Mexican immigrants should be included in future NIMH research. "We need to look at the protective factors, make sure they work for Texans as well as Californians, then try to use them in developing mental health interventions for Mexican Americans," he said. "The key to minority psychiatry is that what we learn from minority populations can be applied to improve the mental health of the general population."

V. BREAKOUT GROUPS

In the Texas Mental Forum's Breakout groups, held the afternoon of December 8, NIMH's stakeholders had the opportunity to provide direct input on the future directions of NIMH research. The topics for the groups was determined by key Texan opinion leaders in advocacy, research, service, and State government. In his charge to the breakout groups, NIMH Director Steven Hyman said their purpose was to explore the question, "How can knowledge that we at NIMH gain from research make a difference for people?"

Each group began with a short introduction by the moderators, who then encouraged free-flowing discussion by the participants. For most of the almost-two-hour sessions, the moderators stepped in only to answer questions about NIMH and to summarize key points in the discussions. At the end of each session, the moderators facilitated a group process that led to a manageable list of specific recommendations for NIMH research priority setting.

A. Breakout Group 1: Building Practice Research: Research That Providers Want

Moderators: Dr. Elizabeth C. Poster, Dean and Professor, University of Texas-Arlington, School of Nursing and Dr. Gustavo Martinez, Chief Executive Officer, Life Management Center for Mental Health and Mental Retardation Services

This group explored how clinicians, family caregivers, and consumers can be an important and rich source of observations and information that could be shared with researchers for study. The session also promoted an exchange of ideas between the research community and the practice that can help identify common practices to determine whether they are really helpful and whether particular avenues of research provide helpful answers.

The moderators worked to focus group discussion around four key questions:

- What would help facilitate a more active exchange of ideas between researchers and clinicians, consumers and caregivers?
- What are the most important practice questions researchers should address?
- What are the most useful ways of sharing practice research findings?
- How do you decide whether or not to use a research recommendation?

The discussion was wide ranging, with a number of suggestions, ideas, and comments on current practice emerging.

Discussion**:** Participants strongly suggested that NIMH and all researchers undertake a much greater effort to make their research available to and usable for clinicians and consumers. In particular, researchers were urged to make sure all research reports are "lay person friendly." One participant suggested that all such reports be written at a 6^{th} grade level. It was also suggested that NIMH could make much better use of the Web, e-mail and listservs to reach a wider public.

Participants drew contrasts between the availability of information about physical illness and mental illness. One participant noted that a great deal of information is available about breast cancer, the need for early detection, and the need for women to check themselves for lumps. However, there are no clear messages available to the public about the early signs of mental illness. An emergency room nurse and educator noted that ER physicians feel they know how to

treat a cardiac patient because they have specific steps and procedures to follow. However, they believe it is much more difficult to assist a mental health patient who are unfamiliar with standard protocols and treatments.

Another participant pointed out how this lack of widely available information can harm treatment. "If I'm given pills and no one explains why I need to take them, I'm less likely to stay on my medication because I don't understand how it is benefiting me," the participant said. Participants suggested that NIMH form coalitions with other interested organizations to enhance getting information out to the public. Mental health coalitions have the capability of reaching wider audiences, and have experience in doing so.

It was pointed out that economic questions pose several problems for mental health practice. Physicians need to see the cost and benefit of mental health treatment before they will be open to recommending patients seek help for mental illness. Managed care providers need to see the cost benefits of mental health services before they will be willing to provide them. One participant framed the problem this way, "We've got to convince caregivers and HMOs that mental health is important, serious and treatable. It's not just 'in your mind.'"

In making suggestions for future directions for research, participants said they would like to see money provided in research grants to reimburse consumers and family members for their time in studies. It is important to have families involved in the research, and without some financial support they may not be able to do so.

It was also suggested that NIMH research not focus on diagnoses, keeping in mind that 100 people diagnosed as depressed, for example, will show very different clinical symptoms. Instead, NIMH was urged to study the dimensions of diseases, rather than focus on making diagnoses, since diagnosis assumes homogeneity in mental illness that is not there. It was also suggested that NIMH focus on dual diagnosis, i.e. on people with diagnoses of both retardation and mental illness.

Research Suggestions:

1. Integrate qualitative dimensions into research, and review current research instruments to see that they adequately capture these dimensions.
2. Go beyond effectiveness research and evaluate interventions in natural setting.
3. Study effectiveness of peer support groups.
4. Assess the different needs and responsiveness to treatment of diverse ethnic groups.
5. Include funding in research proposals to insure that research findings reach consumers and families.
6. Do more co-morbidity research.

Breakout Group 2: Shaping NIMH's Role in Supporting Research in Texas

Moderators: Dr. Charles Bowden, Chairman, Department of Psychiatry, University of Texas Health Science Center at San Antonio and Dr. Marcia Toprac, Office of the Medical Director, Texas Department of Mental Health and Mental Retardation

The moderators aimed to focus the discussion around several key points, including:

- How can NIMH's grant development, application, review, and award process be strengthened to capitalize on research opportunities in Texas and across America?
- NIMH can also compete contracts for research, research development, and dissemination activities. When should such contracting be undertaken and by whom?
- How can NIMH foster partnerships between the research community and the individuals who need research findings for decision making, such as consumers, their families, practitioners, and policymakers?

Discussion: The attendees offered a broad range of suggestions. One participant called attention to the need for more research on the value of support groups. More research might encourage clinicians to make better use of these resources. Similarly, NIMH could play a useful role in educating clinicians, providers, and consumers on the benefits of support group interventions. Moreover, such research could help improve the effectiveness of support group-based treatments.

One participant called for placing more Texans on NIMH review panels, while another said NIMH could play an important role in helping isolated researchers, especially in the border areas of Texas have access to well-funded centers in the state doing important work. This would improve the remote researcher knowledge and help disperse the NIMH research more widely.

The session heard a number of suggestions that NIMH look at non-traditional ways of providing mental health interventions, especially in community-based organizations. NIMH might, for example, promote partnerships between community-based treatment organizations and more traditional academic research centers.

Some consumers pointed out that they needed relevant data to more effectively lobby for increased governmental and private spending on mental health services. They urged NIMH to work harder to disseminate such data to individuals and families.

The discussion also focused on mental health and the Texas judicial system.

Many of the session participants urged NIMH to do more to extend the reach of its research. "NIMH needs to do more to disseminate its findings to policy makers and front line providers," said one. NIMH also should do research to determine ways to educate providers about the results of research and encourage them to implement "best practices."

NIMH was also urged to fund risky projects and seek out researchers outside of the "established" research community and conventional research settings. This approach will not only yield better research, it will also broaden the base of researchers, helping NIMH reach its goal of assuring an adequate research and dissemination capacity.

Research Suggestions:

1. NIMH should support research on interventions in consumer and family-run support groups and other educational efforts.
2. More research is needed on what happens to young people who are in the care of the juvenile system, especially the juvenile judicial system.

3. NIMH should consider funding multidisciplinary projects outside its narrowly defined mission. Research that would pool or bridge some of the missions of diverse government agencies (e.g., SAMHSA, NIAAA, NIDA, and DoJ) would be especially helpful.
4. NIMH should disseminate and communicate its research much more widely, ensuring that the latest research gets into the offices of providers, who are seeing patients.
5. There should be a quicker turnaround for NIMH research review.

Breakout Group 3: Getting to Well: Generating Research on Recovery

Moderators: Mr. Michael Halligan, Executive Director, Texas Mental Health Consumers and Dr. Leticia Lantican, Ph.D. Director, School of Nursing College of Health Sciences, The University of Texas at El Paso

The moderators began the session by asking each person in the room to introduce him or herself. Attendees included providers, consumers and advocates.

Discussion: The session began with at discussion of whether it was possible to develop an operational definition of recovery. A good deal of the discussion centered on employment. Some argued that having a job–volunteer or otherwise–is not a universal benchmark of recovery. They said that recovery is a process not a single endpoint, and cited the example of the physically disabled. "A person may not be able to perform a paying job, but she's still in the process of recovery," said one attendee.

Drs. Halligan and Lantican consolidated the suggestions that emerged from discussion with input from the participants, then produced a working definition of recovery. It includes:

- Having an adult functioning role, including the capacity to love someone
- Applying your abilities somewhere on the professional continuum from volunteering to paying job
- Recovery is a process, not a product
- Individual dignity
- Setting and achieving goals

On the last point, several participants noted that mental illness involves cycles of recovery. Said one, "You just reach a point where you say 'I don't want to live in my illness anymore.' And you start on the path to recovery."

The moderators then began a discussion of how NIMH could improve its research priority setting. The breakout participants came up with a wide range of suggestions:

Consumers should set standards of wellness. One participant suggested that NIMH fund a project comparing one group that has self-generated expectations for a livable wage, independent living, incremental progress with another group, with no such expectations to see which group has a more successful recovery.

Research negative symptoms. One participant said her daughter can see the little pieces and complete small tasks, but she can't put together the big picture. "Is there a way to measure the cognitive recovery of a person with a mental illness?," she asked.

Self-encouragement, or 'inter-individual' motivation as a pathway to recovery.

Research on the gap between what a person with mental illness wants and what the mental health system delivers.

Research on environmental triggers of mental illness.

The Role of Expectations. One participant asked if the impact of external expectations could be compared to internal expectations.

Implementation. Several participants noted that research needs to have a greater connection to implementation. One example cited was that it would be helpful if researchers offered transportation for consumers, since – especially in Texas-- it is virtually impossible to participate in recovery without transportation.

Measuring the interpersonal skills of providers.

Studies on the best practice or administrative models.

Research on the clinicians.

The Effectiveness of Clubhouse or Green Door-type living arrangements. What happens when patients lose services?

Does physical movement reduce aggressiveness? Jan Taylor, (San Antonio Alliance for the Mentally Ill, SAAMI) described the very positive effect on a 60-year-old patient who showed tremendous in her ability to be with others after she got involved in movement exercises. "I was amazed that the combativeness simply left her," said Taylor.

Research Suggestions:

1. What is the relationship between improvement and self-feeling and self-awareness?
2. What is the relationship between expectations and outcomes?
3. What is the role of brain plasticity?
4. What are the critical times in recovery?
5. If illness is acknowledged, does the will to change actually improve the likelihood of recovery?
6. How do dysfunctional people function? What does this mean?
7. How can technology improve the delivery of mental health services?
8. How do people help themselves?
9. How can we promote independent activities outside the mental health system?
10. What is the impact of the interpersonal skills of researchers and other health care providers?
11. Can we measure the impact of programs like the Green Door or Drop-In centers, etc.?
12. What are the effects of physical activity upon recovery?

Breakout Group 4: Research And Underrepresented Minorities–Mental Health Advances For All

Moderators: Dr. Joseph Martinez, Director, Division of Life Sciences, University of Texas at San Antonio and Dr. Regenia Hicks, Deputy Director, Child and Adolescent Services Mental Health and Mental Retardation Authority of Harris County

The breakout participants included representatives from diverse cultures and ethnicities, and practitioners from various settings. The moderators encouraged the participants to focus on five main questions:

- What are the challenges and opportunities regarding the recruitment and retention of underrepresented minorities in mental health research?
- What are the most important domains to study, from multiple perspectives, regarding the help seeking, use and provision of mental health services?
- How are different perspectives incorporated into the research?
- How are the cultures, social networks, and social systems of minorities accounted for in mental health research?
- What have we learned in some ethnic or minority groups that might be relevant to others?

Discussion: One of the clear themes that emerged from the meeting was a challenge to NIMH to do more to broaden the impact of its research. Participants called on NIMH to encourage closer research partnerships between the people who are practicing in the mental health field and those doing research. Such partnerships would be especially helpful in developing tools to study the impact of different cultures on practice.

Participants also called for more research on school-based services for children, especially for studies that looked at how changes in the support infrastructure at school could have positive outcomes. It also was suggested that NIMH could do more to help Texas learn from best practices in other states.

The breakout group called for more NIMH more research on the relationship between acculturation and the incidence of psychological pathologies. The goal would be to determine how acculturation can help and hurt. In addition, participants felt that NIMH should fund more research on culturally competent clinical practices. Several participants said such research would be facilitated if cultural and ethnic minorities were more strongly represented on research bodies.

The session highlighted the fact that Mexican Americans are not likely to seek out mental health services. NIMH should encourage research on what can be done to facilitate help seeking, and examine what strategies work best, several participants said. In particular, participants suggested that NIMH test the hypothesis that there are key gatekeepers in the Hispanic community.

Research should also help uncover what competencies clinicians need in order to work with ethnically and culturally diverse populations. Other participants encouraged NIMH to do more research on peer interventions, attempting to develop measurements of outcomes.

Given the many cuts made in mental health budgets, participants called on NIMH to do research on the effects of these cuts. Several participants discussed the role of faith and called on NIMH to investigate the effects of faith-based programs.

In addition, the participants strongly recommended having regional workshops to discuss the latest research findings, to disperse it to consumers and clinicians who now have trouble learning about it and putting it to use. Finally, participants made a strong recommendation that NIMH help get more women and minorities participating in research.

Research Suggestions:

1. Do more research involving partnerships between practitioners and academic researchers.
2. Investigate the effect of school-based services for children.
3. Make widely available “best practice” information from a variety of states.
4. Study the impact of acculturation on mental health.

5. Do more research on which clinical practices work best with specific groups.
6. Investigate how gatekeepers in Hispanic cultures might be used to increase the utilization by Mexican Americans of mental health services.
7. Research what competencies clinicians need to work with diverse populations.
8. Analyze the effects of budget cuts on people with mental illness.
9. Research the role of faith in mental health treatment.

SIDEBAR

On the Front Lines of Community Mental Health

The Promotoras Program in The *Colonias* of Texas

In the last twenty-five years, a string of almost 1500 impoverished communities, called *Colonias*, have sprung up along the U.S./Mexico border. These unincorporated communities, home to more than 350,000 people, usually lack the most basic infrastructure—sewers, running water, storm drains and paved streets. They have grown in response to a shortage of low-income housing, as well as high birth rates, immigration and migration due to the border industrial boom.

Median annual income in the C*olonias* is estimated at $7,000-$11,000 per household. Typical family size is 5-6 people. The population within C*olonias* appears to be growing by as much as 7%-10% a year.

The *Colonia* residents are isolated, and not only by geography and a lack of physical resources. Most lack English language skills and very, very few understand what types of government and other assistance programs are available to them.

In 1991, the Center for Housing and Urban Development located in the College of Architecture at Texas A&M University began receiving yearly funding from the Texas Legislature to improve the quality of life of *Colonias* residents. The *Colonias* Program is designed to catalyze "community self-development", whereby the majority of the residents become involved in activities to strengthen the social infrastructure of the community, which in turn supports meaningful and appropriate development of the community's physical and economic infrastructure. The program helps *Colonia* residents access education, health, human services, job training, youth and elderly programs available in their areas.

The *Colonias* Program has leveraged funding from the State Legislature by soliciting additional support from a variety of sources including county governments, private companies and organizations and federal agencies. The *Colonias* Program works in partnership with *Colonia* residents, county governments, local, state, and Federal agencies, nonprofit organizations, and several other member institutions of the Texas

A&M University System (including the Texas Engineering Extension Service and Texas Transportation Institute).

In March 1998, the *Colonias* Program launched a new initiative to train local outreach workers called *promotoras*. These women, all of whom live in C*olonias*, make home visits to *colonia* residents to connect them to local education, health, job-training, human services, youth and elderly programs. As part of the their training the *promotoras* meet with social welfare and community agencies (over 100 in each of the three border regions in which the *Colonias* Program operates since the program was started) to learn about the services they provide. They also participate in professional development and training workshops in areas such as Leadership Development; Decision Making, Team Building, Self-Evaluation and Volunteerism; Computer Literacy; English as a Second Language; conversational English and journal writing; Presentation skills; interviewing; and data collection.

In less than two years, the promotoras have made a real difference. Their wide range of accomplishments includes organizing health fairs, creating a summer free lunch program, setting up a food bank, organizing blood drives, and mentoring young people. They have also been very involved in educating *Colonias* residents about mental health services and helping them find the support they need.

On December 6, 1999, NIMH staff met with promotoras and staff of the Texas A&M University *Colonias* Program, as a lead-in to DIALOGUE: TEXAS. NIMH staff provided an overview of NIMH research on depression and bipolar disorders and the mental health of children. They also heard what kinds of assistance the promotoras needed from NIMH.

The promotoras said they saw a lot of depression in the *Colonias.* They traced what they believe is depression to a range of causes including the high percentage of single mothers, spousal abuse, unemployment, the clash of cultures.

The promotoras also pointed to the barriers to treatment that *Colonias* residents face: mental illness continues to have a stigma in the Hispanic community.

In general, the promotoras said they needed more training in how to recognize mental illness and more information both about the nature of different mental illnesses and the most effective treatments. They also suggested using current programs now in place in the *Colonias*, such as Head Start and WIC, to reach out to residents. Finally, they called for more materials on mental illness written to be more accessible to Hispanics.

Breakout Session 5: Talking About Mental Illness and Stigma

Moderators: Ms. Karen King, Consumer, Mental Health Advocate at the Texas Mental Health Consumers and Ms. Lynn Lasky, LMSW Executive Director, National Alliance for the Mentally Ill-Texas

The participants in the session included front-line clinicians, therapists, family members and many consumers. The moderators encouraged the participants to focus on several topics, including:

- What is stigma?
- How does stigma affect us individually and as a society? Medically, economically, and socially?
- What part does the media play?
- What can be done about stigma?

Discussion: One of the central issues discussed in the session was the meaning and context of "stigma." Some of the participants preferred other terms, including "discrimination." Others offered their thoughts on what kinds of remarks by people or what aspects of popular culture could be considered stigmatizing.

Several participants discussed the connection between stigma and the lack of parity in treatment of and insurance coverage for mental illness. Other effects of stigma were also discussed. Stigma affects psychotherapists and other providers, participants said. Stigma also makes it difficult for people with mental disease to get health care, because doctors tend to dismiss physical ailments as "just mental."

Ms. King noted that because people with depression or other mental illness fear stigma, they are often unwilling to admit to symptoms that could be interpreted as mental illness. Instead, they seek treatment for other symptoms and receive unnecessary or misdirected care from doctors, and delay the start of the treatment they need.

Stigma can also harm the mental health of family members of people with mental illness. It was also noted that NIMH research gives hope to people with mental illness who are battling stigma. Explaining

the causes of mental illness demonstrates that it is treatable, and removes its "mystery." Much of the discussion also focused on the role the media plays in promoting stigma and how it might be used to fight stigma.

The session also discussed how to provide better assistance to people with mental illness facing stigma so they can get both mental health services and subsistence help. The participants stressed the importance of advocacy and education. They also suggested holding regional conferences for mental consumers on how to fight stigma, and get help. The conference could involve researchers and clinicians as well, and might well draw support from the pharmaceutical industry.

Research Suggestions:

1. NIMH should support a pilot project "mental health channel," a cable television channel that would have information for consumers, family members and others on mental health. Such a channel could be set up in one community, and researchers would then analyze the statistics on discrimination cases and complaints to see if it had helped to decrease stigma.
2. NIMH researchers should find consumers who are participating in their own care and examine whether it impacts recovery.
3. What long-term effects do school-based programs on decreasing the stigma of mental illnesses have on children?
4. NIMH should study the effects of insurance parity on the treatment and recovery of people with mental illness.
5. NIMH should sponsor research on how people with mental illness can have better access to transportation they need to receive treatment.
6. In general, NIMH should do more research on the effects of stigma: what happens when care is delayed because people are embarrassed to go for treatment? What are the long-term costs when behavioral care is not integrated into health care?

SIDEBAR

Speaking Out for Consumers

James Van Winkle's *Howler*

"With your voice, we can make a difference for persons with mental illness. This is a place for you to HOWL and be heard!"

With this call to arms, James Van Winkle begins each issue of *The Tri-County Mental Health Consumers Howler* newsletter. For over two years, the *Howler* newsletter has reached out to those who struggle with the stigma and loneliness of mental illness. With a circulation of over three hundred in the greater Houston area and a web presence, each issue of *the Howler* includes useful information such as the local Crisis Hot Line contact numbers, an invitation to the bi-monthly peer support group, a profile of a commonly prescribed mental illness medication, and upcoming community events.

Van Winkle's organization, the Tri-County Mental Health Consumers, Inc, brought a group of consumers to the San Antonio Forum to participate in shaping NIMH's research agenda. Van Winkle believed the NIMH San Antonio Forum was a great accomplishment and opportunity, because it was the first time that a group of consumers embarked on such a trip without any staff people and it was also an opportunity to network with other consumers as well as with other stakeholders.

The NIMH San Antonio Forum helped realize the *Howler's* mission to "decrease the stigma of mental illness and give awareness that a person with mental illness is not alone," according to Van Winkle.

The Howler's most important purpose is to act as an empowerment tool, because it is a forum for consumers to express themselves and to tell their own stories about mental illness.
And people are responding to the Howler's call. One subscriber wrote: "I just read your newsletter and wanted to let you know how wonderful it is. I was touched by your every article. I felt happy when I read some, I felt inspired when I read Some, I felt sad when I read some, I felt connected when I read some, and I felt proud when I read it all. You are truly shepherds leading the path. Keep up the good work…"

Van Winkle and *the Howler's* future include a lot of fundraising. With its new 501c(3) status this year, Van Winkle wants to increase services into the larger community, so that consumers have more options than the drop-in center. Van Winkle explained that the most devastating aspect of mental illness is the loss of contact. This hits consumers hard in Texas, because "there is no transit system here. And it causes a lot of shut-ins."

Van Winkle felt that two important areas of research for NIMH were side effects from mental illness medications and Texas' lack of transportation to mental health services. Van Winkle called the budget situation "terrible. Although everyone feels the budget cuts, consumers are especially hurt by it."

VI. RESEARCH PRIORITY SETTING IN THE NEW CENTURY: THE NIMH STRATEGIC PLAN AND THE TEXAS MENTAL HEALTH FORUM, A TOWN HALL MEETING

At the closing session of DIALOGUE: TEXAS, NIMH Director Dr. Steven Hyman praised the attendees for their efforts. "What we learned today," he said, "will be posted on the NIMH Web site for comment, will be discussed by our National Advisory Council, will be discussed by NIMH staff, and will be incorporated into our priority-setting documents." He noted that the forum had produced many excellent suggestions, some of which could be quickly implemented. In particular, he noted that it was especially clear that NIMH had to make its research available not only to mental health clinicians, but to primary care providers.

He was especially appreciative to forum participants for sending the strong message that NIMH should do more to fund research protocols that will be directly relevant to clinicians in their day-to-day work. This may be controversial with some in the research community, he said, who fear this approach means "less rigor." However, he stressed that it is clear NIMH must be willing to take some risks "or we will become irrelevant."

At the "Town Hall Meeting" that preceded Dr. Hyman's remarks, mental health advocate and National Advisory Mental Health Council member Ms. Kathy Cronkite praised NIMH for its efforts to include stakeholders in its research priority-setting process. She noted that her presence on the NIMH Council was another important sign that NIMH was listening to its consumers.

She also called on NIMH to do even more to include patients in all aspects of NIMH's research and agenda setting, and to include patients early on in the process. Without this kind of inclusion, she said, there is a real potential for enormous resources to be wasted on research that works beautifully in a research setting, but doesn't help people in their everyday lives. She countered the argument that including patients in research review groups might give research too

"narrow" a focus, by arguing that patient inclusion is necessary to counter the parochial perspectives of other stakeholders who have an impact on NIMH research.

Dr. Fernando Guerra, Director, San Antonio Metropolitan Mental Health District, thanked NIMH for providing the public health community the opportunity to have an impact on research. He called for a closer connection between public health and mental health, especially at the level of under-served communities. He called attention to a special problem in immigrant communities: immigrants tend to arrive in good health, but mental and physical health conditions tend to deteriorate markedly by the time of the third generation of immigrant families.

Perhaps, he said, one solution might be to develop surveillance and treatment models that link mental health and public health measures. He noted, for example, that pharmacists were being used to perform more and more public health functions in Hispanic communities, and it might be possible to involve them in monitoring community mental health, as well. For example, they could track doses of antidepressants, anti-anxiety and antipsychotic medications. Finally, he called for more research focused on communities, perhaps to identifying factors that lead to good or bad community outcomes and what contributes to "health communities" from a mental health standpoint.

Karen Hale, Commissioner, Texas Department of Mental Health and Mental Retardation, said she hoped DIALOGUE: TEXAS would be the beginning of a dialogue on research that needed to take place. In an era of scarce resources in the public mental health system, she said, it is increasingly incumbent on us to know where to put our dollars. The interventions we choose, she added, must be evidence based, so practitioners will know they have a good chance of being effective.

She noted that Texas faces a population explosion as well as an explosion in the needs of the aged and of children. That population will also be more culturally diverse, she said. These growing needs make it especially important that practitioners, consumers and family members have access to the best scientific information in a format that allows it to be used to improve the lives of the people who need help most.

As noted earlier in this report, one of the major goals of DIALOGUE: TEXAS was to provide input into the NIMH strategic plan. At the final session Dr. John Rush presented the following summary of the recommendations developed at the forum, grouped according to the NIMH goals laid out in the Strategic Plan:

GOAL 1–Understanding Mental Illness. This includes a range of objectives, such as understanding the normal brain processes that underlie cognition, emotion, behavior; and understanding the contributions of developmental and aging processes to brain and behavior and to mental and behavioral disorders, etc.

- Study the dimensions of disease, not just disease categories.
- Study early phases of a disease before they become severe and persistent.
- Research people with mental illness who are in non-treatment systems, especially the juvenile justice system.
- Research what factors are necessary to create a workable definition of recovery.
- Study protective factors. Can we learn from those people who are at risk, but who don't develop illnesses? What are the factors–psychosocial, genetic, etc.–that protect people?
- Study why some people with mental illness function well, while others can't function at all.

GOAL 2–Understanding How to Treat and Prevent Mental Illness. Sample objectives include enhancing research focused on the discovery of new pharmacological and behavioral interventions; determining the best fit of prevention and treatment interventions for use in community settings with complex and diverse populations, etc.

- Study the process, not just the outcome of treatment.
- Study patients as they appear in their varied and heterogeneous forms, not just the patients who get into efficacy trials.
- Study and evaluate peer support groups. For whom are they effective? What kinds are effective? How can we make them more effective?

- Study the people who drop out of treatment. What happens to them? Does dropping out always have a bad result? Should we try to intervene to prevent dropping out?
- Study what provider characteristics and what patient expectations affect recovery.
- Research what factors can lead to recovery.
- Research treatments based on a patient's strengths, not weaknesses.
- Research the role of physical activity in treatment for mental illness.
- Investigate which school-based systems for children work best and for whom.
- Research best practices.
- Study acculturation, and cultural development. How can these be measured? How can these processes be improved?
- Examine what clinical skills and personality skills are associated with better outcomes for minority group patients.
- Take advantage of budget cuts to analyze their effects on patients. Who hurts the most? Do some benefit?
- Study the role of faith and religion in outcomes.

GOAL 3–Assuring an Adequate National Capacity for Research and Dissemination.

Sample objectives include ensuring future research capacity through support of research training and career development in those areas that hold the most promise for the next decade; educating the public about mental illness risk, treatment, and prevention by using the best tools and technology, etc.

- Do more to get research findings into communities, families, and to everyone who needs more information to make informed choices.
- Speed the funding and review process at NIMH.
- Create greater research linkages between the academic system and the public care delivery systems.
- Make information about best practices more widely available.
- Organize more conferences to inform the public about research at the NIMH level.
- Use the media not to stigmatize, but to reduce stigma. Would a change in the media mean more early detection of mental illness? Would it encourage more people to seek treatment?