National Institute of Mental Health
Alliance for Research Progress
July 19, 2004, Bethesda, MD

Introduction

Organized by the National Institute of Mental Health (NIMH) Office of Constituent Relations and Public Liaison (OCRPL), the first NIMH Alliance for Research Progress meeting was held Monday, July 19, 2004 at the Hyatt Regency Bethesda, in Bethesda, MD.

Representatives from organizations and groups whose main focus is to advocate on behalf of patients, families, and others who are directly affected by mental illness attended this meeting. NIMH is keenly aware that persons with mental illnesses, and their families, are the most important stakeholders in the research enterprise. Therefore, the meeting was designed as an open dialogue between NIMH staff and these individuals—or their representatives. Their viewpoints are crucial to advancing the NIMH mission of reducing the burden of mental illness through research on mind, brain, and behavior because they provide a perspective that is essential to building a research agenda that takes advantage of scientific opportunity while being responsive to public health need. The Alliance was smaller than similar meetings hosted by NIMH in the past, such as the Research Roundtables and "outside the beltway" Dialogue meetings. This more compact group allowed a highly interactive format, facilitating a more open and conversational atmosphere, which corresponded with the goal of getting input from these important stakeholders. NIMH is committed to acknowledging, understanding, and working towards solving the incredibly complex questions surrounding the genesis, course, treatment and ultimately the prevention, of mental illnesses. All of these issues are critical to NIMH constituents. Working so closely with all Alliance members fosters the very best science toward the goal of helping those suffering from mental illnesses, and serves to educate the public about the need for future research in basic science, clinical research to develop better therapies, and the translation of that knowledge to effective health services.

Thomas R. Insel, M.D., NIMH Director, opened this year's meeting with an overview of the ongoing NIMH reorganization and the Alliance participants' place in this exciting environment. http://www.nimh.nih.gov/researchfunding/reorganization.cfm After opening remarks, participants were given time to interact with each other and NIMH staff members.

After the networking break, Dr. Elias Zerhouni, M.D., Director of the National Institutes of Health (NIH), gave his keynote address. This address was followed by breakout sessions where participants discussed one of three topics: The Public Trust Initiative, Science to Service, and Clinical Trials. Open discussion encompassing the entire program took place during the final hour of the Alliance meeting.

Opening Address, Dr. Insel

Dr. Insel’s opening address outlined changes at NIMH and expressed his hope that this meeting would be an important component of NIMH’s overall priority setting efforts. There have been other components in this inclusive approach to priority setting that are also directed at ensuring getting the widest possible range of viewpoints from all of NIMH’s major stakeholders. For example, Dr. Insel described his request that NIMH’s legislatively mandated advisory body, the National Advisory Mental Health Council (NAMHC), form a workgroup to scrutinize NIMH’s current portfolio of basic research to help him identify areas that represented the best opportunities for relevance to the NIMH mission, scientific opportunity, and innovation. This group broke into two: the first looked at NIMH’s entire behavioral science portfolio; the second looked at basic and cellular neuroscience. At the time of the Alliance Meeting, the Basic Brain and Behavioral Science Workgroup report had been released (http://www.nimh.nih.gov/council/bbbsresearch.pdf).

Changes at NIMH also reflect the NIH Roadmap, which represents a new paradigm for supporting research at NIH (http://nihroadmap.nih.gov/). Particular attention is being given to avenues of research where there is a high potential for progress or need for increased effort. Two very exciting parts of the Roadmap are the emphasis on collaborative research and reengineering the clinical research enterprise.

Translational research is receiving greater focus and is part of a revitalized effort to bring science to practice in the NIMH reorganization (http://www.nimh.nih.gov/researchfunding/reorganization.cfm). Translational research encompassed two major steps, and NIMH is focusing efforts in both. First, it is important to bring discoveries made at the “bench” to the bedside. For example, translational research seeks to identify biomarkers, or biological differences that all individuals with an illness share, and then develop diagnostic tests for that marker.

Research at NIMH also seeks to take “bedside” use into more widespread implementation. A new effort between NIH and the Substance Abuse and Mental Health Services Administration (SAMHSA), often referred to as the Science to Service initiative, seeks to do just that. Research-based treatments have been developed that are very effective but passing these new therapies into common practice has proved difficult. NIMH, the National Institute of Alcohol Abuse and Alcoholism (NIAAA) and the National Institute of Drug Abuse (NIDA), have a reenergized commitment to working with SAMHSA as well as service providers, advocacy groups, and many others to bring state of the art research into clinical practice.

Translational research also attempts to answer important treatment questions such as:

- Do new, more expensive drugs work better than older drugs?

- What is the right treatment for individuals who do not respond to initial drug therapy?

Answers to these questions are essential; clinicians make these decisions daily and research clarification is necessary to improve clinical practice, patient care, treatment efficacy, and cost-effectiveness.

Other NIMH initiatives include: (a) new Requests for Applications (RFAs) on important public health topics that have been previously under-represented in the NIMH portfolio http://www.nimh.nih.gov/grants/rfa.cfm; (b) the Men and Depression Media Campaign http://menanddepression.nimh.nih.gov/; (c) the Neuroscience Blueprint; and (d) the NIH-wide Public Trust Initiative.

Following Dr. Insel's remarks, audience members were invited to participate in a question and answer session. Two topics in particular, disease co-occurrence and research coordination, inspired the most energized discussion.

Disease Co-occurrence

Dr. Ann Ellison spoke on behalf of her organization, Children and Adults with Attention Deficit Disorder (CHADD). She noted that attention deficit commonly occurs with other diseases but that clinical trials often exclude individuals with dual diagnoses. Jerry Reed of the Suicide Prevention Action Network USA (SPAN) reported that the same is true of suicide survivors. Since most suicide is a consequence of serious mental illnesses, the study of survivors could greatly inform the evidence base of prevention and treatments.

Dr. Insel agreed and, given the prevalence of dual diagnoses, noted that many research exclusions have the effect of not mirroring conditions in the "real world." Likewise, an increasingly common practice, often referred to as polypharmacy, or prescribing many drugs together to treat one person's symptoms, is not guided by research data. Government-sponsored research to better understand such combined interventions is critically needed because it is not the type of work that industry is inclined to support.

Ms. Amy Comstock with the Parkinson's Action Network elaborated using the high prevalence of depression co-occurring with Parkinson's disease as an example. The Parkinson's community is frustrated that depression in Parkinson's patients is often undiagnosed and that the relations between these two diseases are unknown. A whole-human approach to disease studies would be helpful and more reflective of those suffering with Parkinson's. As a final point, Ms. Comstock suggested that curing diseases would build public trust faster than anything else. Many in the audience supported this observation.

Research Coordination

Dr. Clara Lajonchere from the Autism Genetic Resource Exchange (AGRE) noted that a lot of effort overlap exists in autism research and urged coordination and efficient use of research dollars. Dr. Insel responded that NIMH recognizes that data sharing will move science forward more quickly, and has committed to increasing the sharing of data among NIMH-supported researchers. In addition, priority setting is a crucial component for ensuring the efficient use of funds. However, coordination is often antithetical to current scientific tradition where scientists "own" their data and discoveries, and through this ownership, build their research careers, are awarded grants, and earn tenure. While scientific culture does not always embrace data-sharing, the goals of the community require that these efforts be discussed, considered carefully, encouraged and perhaps, at times, required.

One attendee stressed that a change in scientific culture was necessary noting that, "We have all too long done business as usual. Business as usual is not going to get us to cures for our disorders."

Keynote Address, Dr. Zerhouni

Dr. Elias Zerhouni, M.D. began his keynote address by commenting that throughout his career he thought there was not enough communication and interaction between those who conduct research and those served by research. Consequently he expressed his pleasure to be at a meeting where that was the single purpose. Although the advantages of interactions seem obvious, the lack of serious efforts in this area has persisted even though patient-oriented research is impossible without the involvement of the people being directly affected. This characteristic of the research enterprise is probably the result of a focus on more acute, short-term, and lethal conditions that were the focus of early medical research. In that kind of research human interaction was a minor consideration. Today, 75% of medical dollars are spent on chronic diseases. It is time for medical research to reflect this shift. Dr. Zerhouni told participants "There is a scientific imperative to have a better understanding and communication with you, and there is obviously a right-thing-to-do imperative. We are funded by taxpayers' dollars, and we need to make sure that whatever we do responds to taxpayer needs and that we do this in a transparent fashion that inspires trust and confidence."

The new Public Trust Initiative began as a way of inspiring public trust and confidence in the NIH by increasing the interactions between the scientists and the people they serve. This effort is targeted toward maintaining a focus on public health needs by involving citizens in research design from the very beginning. Dr. Zerhouni used cystic fibrosis (CF) as a successful example of disease fighting through an organized network. The CF national registry contains information on 30,000 individuals who suffer with this disease. Aside from a registry, laboratory and test protocols have been standardized and an elaborate dissemination network has been developed so that science translates to practice quickly. As a result, in the last 25 years, life expectancy for individuals with CF has gone from 10 to 40 years thus demonstrating the efficacy of this approach. This is a model for building "research engines" through a community of scientists, patients, and families working together toward a common goal.

Dr. Zerhouni emphasized that NIH has a lot of work to do. As demonstration he polled the audience by asking, "how many of you think we know 90% of what we need to know to be effective in developing treatments and cures? No member of the audience replied to that, nor when he asked about 50%, and about 25%. "Ten?" he queried and some members of the audience raised their hands to which he responded, "well, you represent exactly the same answer I received from these top-notch scientists and CEOs" to whom he had spoken recently. In that same audience were biotech investment bankers. He asked them how they justified investing in a group of people who know only 10% of what they need to know to cure disease. Although an interesting story, it is a direct and sometimes startling reflection of reality. The answer to that puzzling question, "why invest?" is that the potential reward is so great.

Dr. Zerhouni ended his keynote address by applauding the 14 institutes at NIH that are working together on the Blueprint for Neurosciences in the 21st Century. This effort to coordinate neuroscience research is another example of a strengthened commitment that NIH has to collaborative work. In this way, discoveries in one field can quickly and positively impact advances in the others through integration across disciplines, institutes, and diseases.

Keynote Address Question and Answer

Dr. Insel explained to Dr. Zerhouni that during an earlier discussion, some participants had brought up problems with changing practitioners' behavior to take advantage of medical advances. In response, Dr. Zerhouni stated his view that most often, information is fragmented and that behavior change takes place when knowledge coordinates into a cumulative, compelling base. One effort outlined in the Roadmap, calls for the development of the National Electronic Clinical Trial and Research System (NECTRS). This should assist in addressing issues of knowledge transfer, disease co-occurrence, and polypharmacy because the language of NECTRS will be standardized so that data elements are comparable from one project to another. This is an expensive solution, now estimated to be a $6 billion investment.

Ms. Mary Guardino, of Freedom from Fear, noted that participant recruitment can be a challenge and asked what NIH was doing to address this challenge. Dr. Zerhouni agreed that encouraging patients to participate in clinical trials has always been a difficult part of NIH's work. The Roadmap outlines the NIH Clinical Research Associate Corps, which is designed to train and involve physicians in clinical research.

Many comments centered on the allocation of research dollars at NIH. Some advocates expressed the sense that NIH methods of budget distribution are opaque, that there is double counting, and no or unclear logic. Dr. Zerhouni addressed all of these issues. What appears to be double counting occurs because much research “counts” in multiple categories and funding is determined after carefully considering a variety of factors. Fund distribution is predominantly determined by considering public health need and scientific excellence. Thus, answering the question “How do you know if NIH is investing properly?” becomes very difficult to answer. Engaging members of the public in decision making and enhancing their trust in the research enterprise are ways to address such complaints and to create transparency.

Dr. Zerhouni ended his comments by describing funding realities at NIH. Although the budget has doubled over the last five years, so have missions and responsibilities. NIH cannot do every type of research and service delivery research is particularly expensive. He concluded that NIH is carefully considering and coordinating research efforts to best achieve mission goals. He understands that NIH’s role is to conduct the best science and support excellent research at institutions throughout the nation, while considering public health imperatives.

After Dr. Zerhouni spoke, the plenary session broke into smaller groups to discuss three topics: The NIH Public Trust Initiative; NIMH Science to Service Efforts; and Clinical Trials: The Next Generation. These sessions began with an NIMH facilitator giving an issue overview accompanied by slides. The topic was then open to discussion.

Public Trust Initiative

Facilitated by Mayada Akil, MD and Gemma Weiblinger

The Public Trust Initiative breakout was facilitated by Dr. Akil, Senior Advisor, NIMH Office of Science Policy and Program Planning and Gemma Weiblinger, Director of OCRPL. The session began with an historical overview. When Dr. Zerhouni arrived at NIH he felt that trust between NIH, patients, and advocacy groups was of the utmost importance and that it needed to be strengthened. Improving these relationships became one of the bedrocks of his agenda as director (http://copr.nih.gov/reports/enhancing_public_input.asp). After a brief topical overview, the audience participated in lively discussions and brainstorming sessions.

One participant suggested that to build public trust NIH should utilize the service organizations more often and in an organized manner as these groups would be happy to help the research enterprise. In return NIH needs to translate publications into language consumers, families, and research participants can understand. Public trust and confidence can be built by NIH pairing with patient and family advocacy organizations to conduct needs surveys of consumers and by addressing those issues.

Because of the stigma associated with mental illnesses and also to put mental health into the public’s consciousness, NIMH should invest in a mental health media campaign. The suggested campaign would not be about any particular illness but would define mental health, describe how to stay mentally healthy, how to attain mental health care, and when to seek care. The purpose would be to change the way the public thinks about mental health and at the same time, reduce stigma. NIH should also work to reduce stigma and try to get media portrayals of mental illness to be more accurate and less sensational.

Participants suggested a number of ways to increase the public trust. These include:

- Advertising NIMH commitment to service through highlighting its work with community organizations such as the Outreach Partnership Program and the Dialogue meetings.
- Telling organization representatives exactly what NIMH knows about particular diseases, in a practical and concrete manner.
- Marketing the Institute to improve the public understanding of its work, mission, the research process and to provide easy access to research findings.
- Informing research participants about results of studies in plain language—providing "white papers" for patients, families and health care providers.
- Explaining long-term research plans to constituent groups.
- Understanding that a cure can take years, NIH can focus research efforts on disease symptoms that have a particularly negative impact on quality of life and disseminate those findings.

Mr. Reed of the Suicide Prevention Network mentioned that the populations most relevant to NIMH interests are populations that often trust advocacy groups. Through partnering with these organizations, NIMH can build its public profile and community trust. The benefit can be mutual. NIMH should use the groups to engage people in the research enterprise, educate them about the purpose, benefits, and functions of research, and educate them about specific research findings on particular conditions.

An audience member suggested that NIMH put out balanced topic pamphlets and make them available in physician offices. Citing a piece on children and pharmaceuticals as an example, it was noted that NIMH is a trusted source of unbiased information. Even if there is no straightforward correct answer to an issue, science-based information is useful so that individuals can make their own informed decisions. Distributing these documents to physician offices is beneficial for many reasons: people have time to read, they are thinking about the particular topic at the time, patients can engage their physicians in a discussion, and the information enclosed therein can serve as an educational alternative to product documentation.

The session ended with a comment on the title "Public Trust Initiative." The name might be misleading in that the goal of the initiative is not so much trust as it is public engagement and education.

Clinical Trials: The Next Generation

Facilitated by Grayson Norquist, MD

Dr. Norquist, Director of the NIMH Division of Services & Intervention Research, began this breakout by explaining that most NIH research is investigator driven. That is, an investigator thinks of an idea and the best of those ideas are funded through a very rigorous and competitive peer review process. Sometimes NIH decides that a particular area of research needs to be done quickly and that work is generally funded through a contract. This is how some of the larger effectiveness trials have been conducted such as the Systematic Treatment Enhancement Program for Bipolar Disorder (STEP BD). This study is still in its recruitment phase and was designed to compare standard care to potential care options, over time. STEP BD met its underserved population goal because the project is largely community based.

The Clinical Antipsychotic Trials of Intervention Effectiveness Project (CATIE), which has completed recruitment, is a study of schizophrenia and Alzheimer's disease. Fifty community sites have been selected; among them are public health systems and academic settings that have never before participated in clinical research. The study tests the efficacy of currently used, competing antipsychotic medications. Dr. Norquist noted that NIH must conduct studies such as these because drug companies would never want to compare their drugs to a competitor's. STEP BD, similarly, is comparing all available bipolar disorder drugs.

Sequenced Treatment Alternatives to Relieve Depression (STAR*D) is a large study of over 4,000 people with treatment-resistant depression. Half of the sites are primary care clinics because this is where a lot of people with depression are treated. Mainly designed to provide an evidence base for the treatment of depression, this study will address a number of questions such as when to increase drug dose or change drug class.

The Treatments for Adolescents with Depression Study (TADS) is a large, multi-site, effectiveness clinical trial meant to address an urgent public health problem. The 12-week findings were published in the August 25th issue of the Journal of the American Medical Association (JAMA) (http://www.nimh.nih.gov/press/prtads.cfm). These results showed that cognitive-behavioral therapy (CBT) combined with Fluoxetine, an antidepressant commonly known as Prozac®, provided better outcomes than either CBT or Fluoxetine alone or placebo. One audience member was particularly impressed with TADS' methodological design and urged NIMH to follow these children into adulthood. Such an extension of the study would provide useful insight into the path that childhood mental disorders take over the course of development and thus will help elucidate successful paths for children with these disorder to become healthy, productive adults.

One final benefit of all of these study designs is that, because they take place in real clinics, the practices being investigated are already in the community thus knowledge dissemination is part of study design. Describing the future of clinical trials, Dr. Insel told attendees, "Dr. Zerhouni has really developed this concept of communities in research, which would be that you could have thousands of partnerships, with everyone from docs in private practice to community health clinics, to HMOs across the country, in which there would be an effort to involve patients from across the medical spectrum in clinical trials. Every patient would become a participant."

Clinical Trials Question & Answer Session

One participant noted that user-friendly materials and web sites are extremely necessary for successfully involving patients in research. Although the NIMH web site lists all studies, a better option would be a flyer with a phone number and specific contact name. It was further noted that having the information only on the website will select out a large number of people who do not have access to computers.

Dr. Norquist stressed that community feedback is vital to the success of clinical trials. Because they are very expensive and NIH has limited funds, community response or feedback about what questions are particularly important and pressing will help with priority setting. These studies are designed to address what works best of the currently available options and getting this information into practice as fast as possible.

Dr. Insel informed participants that some members of the NAMHC clinical trials workgroup have ties to the pharmaceutical industry and he asked if that were bothersome. One participant noted that like NIH, pharmaceutical companies seek out the best researchers to consult with and to conduct their research and these are the exact people who should be participating in the process.

Science to service: A step in transforming mental health

Facilitated by Junius Gonzales, MD

Dr. Gonzales, Chief of the Services Research Branch in the NIMH Division of Services & Intervention Research, chaired this breakout session and began by describing the origins of the Science to Service Initiative and setting it in historical context. This federal initiative began in 1999, following a study by the NAMHC that resulted in a report on bridging science and service and how to bring clinical treatments and services closer together. In addition, SAMHSA has partnered with NIH to systematize the behavioral health research that is being conducted on alcohol, drug abuse, and mental health and to bring that research to practice in a better and more coordinated way. SAMHSA has also created a new mechanism to fund "services to science" grants. An example of how this initiative works is an ongoing Request for Applications (RFA) between SAMHSA and the three main NIH institutes that conduct research on behavioral health (NIMH, NIDA and NIAAA).

(RFA-MH-05-004: State Implementation of Evidence-Based Practices II - Bridging Science And Service http://grants2.nih.gov/grants/guide/rfa-files/RFA-MH-05-004.html) This effort started with a technical assistance workshop for potential research teams. Multiple stakeholders, including researchers, administrators, clinicians, and family members had to be included in the research team in order for the team to be eligible to participate in this exciting workshop. The workshop was a tremendous success that should result in excellent applications.

Another joint NIH – SAMHSA venture involved state mental health service systems in planning grants to have state mental health administrators think about implementing evidence-based practices in their states, including overcoming related obstacles. These projects were planned in consultation with consumers, administrators, and others and this program has served as a model to other institutes.

Science to Service Discussion

In response to Dr. Gonzales' presentation, Mr. Don Clark of the Depression and Related Affective Disorders Association (DRADA) pondered if there was a bit of wheel reinvention in the NIMH initiative. Many of the nonprofits have endeavored to get knowledge to patients, families, and consumers and that perhaps a better role for NIMH is to team with the non-profits and support these efforts. A partnership with NIMH would benefit the members of these non-profits by, for example, having plain-English translations of research findings linked to these web sites. Dr. Gonzales responded that dissemination is very important and that yes, often groups are doubling efforts and do not always communicate their work with others. Non-profits and scientists have to be more economical and efficient with information transmission. For NIMH the challenge is getting researchers to do meaningful, relevant research and engage stakeholders in the process.

Michelle Alonso of the Anxiety Disorders Association of America mentioned that in order for NIMH to move science into practice, it should train front-line service delivery personnel such as school nurses, primary care physicians, local clinics, and community centers. Dr. Gonzales noted that NIH primarily supports research while SAMHSA primarily funds service delivery, but neither is really focused on funding the types of training that will bring the latest scientific discoveries into daily clinical practice. That is a gap that is not adequately addressed at the federal level. Two participants offered examples of the non-profits organizing courses for communities. Both were targeted educational workshops designed to build awareness while highlighting symptoms and treatment options. These educational sessions were offered in such a way that participants could receive continuing education credits (CEs) for their participation. One role for NIMH and/or SAMHSA would be to offer small grants to non-profits so that they can conduct or expand this work.

Dissemination was another topic that was widely discussed in this session. Participants shared some of the work they were doing. One group has an e-mail network of thousands of health professions who are e-mailed new research findings and treatment options. Another discussed his group's user-friendly guide to research participation that is geared to families. Because his group awards research grants, each grant application must be accompanied by a reader-friendly synopsis in plain English. This synopsis goes into a newsletter that reaches thousands of prospective participants. Furthermore, their conference has reduced rates for consumers.

CHADD administers a clearinghouse of evidence-based-practice (EBP) for treating attention deficits, publishes a magazine that presents research in a family-friendly way, conducts family forums to educate underserved populations about EBP, conducts parent-to-parent training programs, and maintains an informative and accessible website.

The Child and Adolescent Bipolar Foundation has a list of all related approved studies, covers conferences and reports the proceedings in a family-friendly way including both research and treatment options. They produce topic briefs that parents can present to their children's medical professionals and others who help manage their children's condition.

Several participants suggested that NIMH might have to "think outside of the box" when it comes to recruiting minority groups to participate in clinical trials. Possible participants are not aware that screenings and state of the art work-ups are often free in trials and that sometimes compensation for time is provided. Letting members know about all treatment options is a responsibility of the groups as is explaining that research helps the science of treatment advance. Poorly practiced medicine has engendered a lack of trust in some communities so it is particularly important that minority-representative groups engage in public education and recruitment efforts related to clinical trials.

Moving Forward

Consumers of mental health care are the most important stakeholders in the research enterprise at NIMH. During the meeting it became clear that Alliance members are ready and willing to work with NIMH to support exceptional science by sharing their research needs and by educating the public about the value of research in basic science, clinical therapies, and health services.

This meeting also provided an excellent venue for the groups to showcase their efforts. This sharing could increase the efficacy of other efforts and possibly lay the groundwork for collaboration. We at NIMH consider the consumers, and groups who represent them, to be our core constituents and we are committed to maintaining and strengthening existing relationships with these constituents and building new ones.

NIMH has a history of outreach upon which we build. Over many years, we have conducted meetings like this one with different constituency groups. During the Dialogue meetings NIMH staff come together with communities to share thoughts and plan collaborations. On a more frequent basis, NIMH communicates with constituents through the Outreach Partnership Program (OPP) http://www.nimh.nih.gov/outreach/partners/index.cfm. Through the OPP, NIMH has a contact in every state and the District of Colombia to help with research dissemination, public education, and to encourage research participation. The program also consists of national, state, and local organizations which are committed to these same efforts. NIMH publications are distributed throughout the country by our Outreach Partners. During the Alliance meeting many commented that NIMH has a responsibility to circulate research findings in easy to understand language. NIMH has a vast set of publications on its website designed to educate the public about mental health. Most publications are available in PDF format through this website: http://www.nimh.nih.gov/publicat/index.cfm.

NIMH faces an enormous challenge: to reduce the burden of mental and behavioral disorders through research on mind, brain, and behavior. To do so, the current mental health care system must be transformed, as called for in the President's New Freedom Commission on Mental Health; it is critical to improve the delivery of evidence-based treatments that already exist directly to communities. But equally important, NIMH is reorganizing, prioritizing, and seeking vital input from stakeholders as it supports the development of treatments that more effectively reduce suffering and improve recovery for people with mental illnesses such as schizophrenia, bipolar disorder, depression, anxiety disorders, and autism. The need is vast: mental disorders account for four of the top five causes of premature death and disability among 15-44 year olds in the Western world and are equally destructive in other age groups. For many of the disorders, there is some form of treatment, but for most there is no cure. NIMH's goal is to generate research that will enable us to develop more effective and more rational treatments, and, eventually, routinely expect the prevention of and recovery from mental disorders. To achieve this, we must work together with all of our stakeholders to advance the medical research that will enable us to fully exploit recent scientific breakthroughs, increase cross-disciplinary collaboration, and facilitate the translation of basic science discoveries into new interventions. Working together we can envision a future that reaches all the way to cures.

Next Steps

Within a month after the meeting in July 2004, Dr. Insel sent a list of follow-up items from the meeting to the Alliance participants (and later to all the original invitees who were unable to attend.). The list included action taken or to be taken with respect to the item; Dr. Insel also asked for comments from both groups.

Follow-up items included a request for additional meetings. In response, NIMH will host another Alliance meeting in January 2005 based on the suggestion to have frequent updates about NIMH's latest research efforts, with a special emphasis on the most significant achievements, delivered in clear, readily understood language. Such efforts may have the added benefit of moving research findings into widespread practice quickly. As one Alliance member indicated, often it is the members of their organizations—people who are directly affected by the diseases being investigated — who prompt changes in treatment practice and service delivery. It is often their members who demand that providers familiarize themselves with the latest evidence-based information. NIMH will convene Alliance members for the primary purpose of having those who are actually doing the research give updates on what they have found. After research briefings, audience members will have an opportunity to ask specific questions of the scientists. This kind of collaboration should enable Alliance members to educate their own members, who can take this valuable knowledge into their individual communities.

Other specific suggestions that NIMH is actively pursuing through its restructuring and research planning include:

- Developing a more transparent approach to research planning so that interested parties can see where there are gaps in research efforts.

- Ensuring continuity from science to service. It is not enough to take basic research findings and get them "to the bedside," although this is a critical first step. There is a pressing need to see that this vital knowledge gets into widespread community use. While the coordinated efforts of Alliance members and NIMH assist in this, it is not enough. In July, Alliance members heard about what is commonly referred to as the "Science to Service" initiative between NIH institutes and SAMHSA. This ongoing, vibrant effort is strengthened by the commitment of the two federal agencies and researchers to work closely with patients and families. Alliance members and their organizations have a clear role in the "Science to Service" initiative.

- Redefining and measuring outcomes other than symptom reduction. One of NIMH's largest and more aggressive efforts is the current program to facilitate the development of medications for schizophrenia that will target entirely new facets of the disease. Current medications can alleviate the "positive" disease symptoms, such as hallucinations and psychoses, but it is often the cognitive deficits—or "negative" symptoms such as flat affect and social isolation—that cause the most disability. Working together, the NIMH and the Food and Drug Administration are seeking ways to target these aspects of the disease so that patients can once again become active participants in society, seek and retain employment, and become productive members of society.

- Changing the way research is conceptualized by both scientists and communities. Research should be *with,* not *on,* people. NIMH seeks to increase public trust and participation in the research enterprise. There are many ongoing efforts, both within NIMH and in NIH as a whole, to do this. Dr. Zerhouni has named “Reinventing the Clinical Enterprise” as one of the foundations of his groundbreaking Roadmap, so that people in communities, including family physicians and patients, can have the opportunity to participate in clinical research. As a part of this effort, Dr. Zerhouni has launched his Public Trust Initiative involving all NIH institutes—in which NIMH has a leading role. Internally, NIMH is working hard to become more transparent by re-doubling its public dialogue and interaction efforts through sponsoring public dialogue meetings, Alliance and Research Roundtable meetings, the Outreach Partnership Program, and by including public members on review committees for clinical trials and services-related research proposals.

- Improving the NIMH web site and other communication activities. As a part of its continuing commitment to improve, the entire NIMH web site was recently redesigned. In addition there is an ongoing effort to review all current publications for accessibility and ease of use. To help with this, Dr. Insel asked Alliance participants to review the NIMH web site and let us know which documents would benefit from being rewritten on a different level of complexity.

These are only some of the specific suggestions and follow-up items from the lively and useful dialogue at the first Alliance meeting. In response to Alliance members’ requests for additional meetings, NIMH is hoping to have these meetings twice a year. The Summer meeting will be devoted almost solely to dialogue, allowing participants to interact directly with the Director of NIMH and senior staff. This would include plenary sessions and breakout--and would emphasize allowing--indeed soliciting--feedback from Alliance members. The second, Winter, meeting would also feature dialogue, but its main purpose would be to update Alliance members on the latest research advances by grantees and others supported by NIMH. Again, this is in direct response to earlier input from Alliance members.

As a publicly funded and supported agency, NIMH fully realizes its responsibility to its constituency groups—especially those who represent patients and families who live with mental disorders and their impact each and every day. While it is essential that NIMH be a careful steward of public funds and public trust, it must do so with a keen eye toward public health need, especially as it is expressed by those who bear the greatest burden of mental illnesses. We at NIMH intend to keep that public trust, and to make every attempt to remain open to our constituents through frequent direct dialogue and interaction.

Alliance for Research Progress

NIMH Director, Thomas R. Insel, M.D., listens to NIH Director Elias Zerhouni, M.D.

Breakout Groups

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NIMH
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