The Campaign for Mental Health Reform: A New Advocacy Partnership

The work of the President's New Freedom Commission on Mental Health may bring many changes in the mental health landscape. Commission Chair Michael Hogan and others are pointing the way to some of these changes in their articles in this special section. On one front, however, there has already been significant movement, and it is worth noting both why this has happened and what it portends.

Soon after President Bush created the Commission, the chief executive officers of four nationally prominent Washington-based mental health advocacy organizations began, from their very different perspectives, to think about how they could take advantage of the once-in-a-generation opportunity that the Commission's work would present. They reasoned that if the mental health community could mobilize its advocacy resources around a set of policy objectives designed to move toward the goals outlined in the Commission's report, it could, in turn, help public mental health systems to become more streamlined, user friendly, and truly focused on fostering recovery and resilience among those whom they are charged to serve.

The four organizations initiating this discussion—the National Alliance for the Mentally Ill (NAMI), the Bazelon Center for Mental Health Law, the National Mental Health Association (NMHA), and the National Association of State Mental Health Program Directors (NASMHPD)—examined their own priorities and matched them with what they heard emanating from the Commission. They agreed that it would be important to present a unified response to the Commission's report and to find new ways to demonstrate to the decision makers who help shape America's public mental health policy both the urgency of need and the promise of effective services.

During the public comment session at the January 2003 Commission meeting, the potential strength of a united advocacy approach became evident. Chris Koyanagi of the Bazelon Center presented a series of legislative proposals to the Commission on behalf of nine Washington-based public mental health policy organizations. Specifically, these groups had achieved consensus on proposals concerning employment and disability benefits, child and adolescent service system issues, co-occurring mental health and substance use disorders, the intersection of the criminal and juvenile justice systems and mental health systems, evidence-based practice and research, housing, workforce development, Medicaid, and Medicare.

What was extraordinary about this presentation was not just that the organizations had reached agreement, but that they had done so in policy areas that are complex and have historically been prone to factionalized approaches. The significance of this unified presentation was not lost on Commission Chair Hogan and the other commissioners who were present. They enthusiastically suggested that such an approach was needed in the follow-up to their work.

The unity of the advocates at that point in time was important, but there was no guarantee that it would last, as skeptics were quick to point out. The advocates pondered the idea of creating a more formal mechanism to help move forward with the Commission's recommendations. Although they were looking for a vehicle to demonstrate the common commitment of a number of organizations, they felt strongly that the last thing the field needs is simply another coalition. For this effort to succeed, it needed not only to credibly represent disparate organizations but also to be able to act quickly. It needed to be strategic and at the same time opportunistic.

Other fields provided examples and inspiration. For instance, the Campaign for Tobacco Free Kids is the effort of a very different advocacy community to convert a largely ignored policy issue into a national public health priority. There was much for the mental health advocates to learn—or borrow—from this and similar initiatives, including the notion of a "campaign." This was the idea they seized on. As the release date for the Commission's report neared, the Campaign for Mental Health Reform began to take shape.

The campaign was created by the four organizations noted above—NAMI, the Bazelon Center, NMHA, and NASMHPD. However, it was understood from the outset that the campaign should be a partnership of a wider group of public mental health policy organizations. Organizations that have joined the campaign include those representing consumers (the National Mental Health Consumers Self-Help Clearinghouse, the National Empowerment Center, the Consumer Organization and Networking Technical Assistance Center [CONTAC], and the Depression and Bipolar Support Alliance), providers (the National Council for Community Behavioral Healthcare, the National Association of County Behavioral Health Directors, and the International Association of Psychosocial

Rehabilitation Services), and the guilds (the American Psychiatric Association and the American Psychological Association), along with several organizations with special interests (Children and Adults With Attention-Deficit/Hyperactivity Disorder [CHADD], the Federation of Families for Children's Mental Health, and the Suicide Prevention Action Network). This list may well have expanded by the time this article goes to press. As the campaign grows larger, it will face the challenge of ensuring that all viewpoints are taken into consideration while maintaining its ability to act quickly on specific fast-breaking legislative and administrative issues.

The campaign was created to focus on federal policy. Its plan is to identify recommendations of the Commission on which traction can be achieved inside the Beltway and then to put the weight of the mental health advocacy community behind them. Issues on which the campaign can weigh in include the reauthorization of the Substance Abuse and Mental Health Services Administration (SAMHSA), funding for the Mental Health Block Grant, Medicaid, Medicare, reauthorization of the Rehabilitation Act, and funding for housing programs.

If the Commission's report is to be an effective catalyst for making mental health a national priority, a central goal of the campaign must be to show the rest of the policy-making world that the mental health field stands behind the Commission's recommendations. Many of the policies and much of the funding that affect adults with mental illnesses and children with serious emotional disturbances now come from government agencies whose primary focus is not on mental illness. It is important for these agencies and for the members of Congress who oversee and fund them to understand that the mental health field is in agreement on the need for appropriate policies on education, employment, prisoner reentry, and housing. Much as the Commission's report focuses on all agencies and programs that have an impact on the lives of people with mental illnesses, so too will the campaign focus on the broad array of issues and programs relevant to people with mental illnesses, including Medicaid, criminal justice, education, housing, and vocational rehabilitation.

Some thought has also been given to the appropriate role of the campaign in addressing state and local issues, because many of the Commission's recommendations are ultimately aimed at the state and local levels. The advocacy terrain differs noticeably from state to state, and campaign leaders concluded that the model of collaboration and the principles on which campaign policies rest are the most useful tools they can make available to advocates in state and local jurisdictions. The founding organizations have also made a commitment to use their technical assistance capabilities to help state-based advocates in policy development and other activities that will lead to implementation of the Commission's recommendations.

So, what will the Campaign for Mental Health Reform achieve? And how does it plan to do it? Before the campaign began to work out its policies, it adopted underlying principles to act as anchors for all the work to come. These principles are based in large measure on a preliminary understanding of what the Commission's report would say. They are specific, yet simple and indisputable—at least among the campaign partners.

The campaign insists that mental illnesses be treated with the same urgency as all other medical illnesses; it has adopted the Commission's message that mental health is fundamental to health. The campaign calls for national leadership and will promote specific policies to align now-fragmented systems and achieve markedly improved quality in service delivery. The campaign's immediate purpose is to address specifically what the federal government should do to ensure that public systems close gaps and support comprehensive approaches that cross many current systems.

These policy initiatives will be based on themes that incorporate shared priorities: equal access to mental health care, promotion of recovery and full community participation of consumers and family members in all systems of care, the need for a strong safety net, strengthened quality of care, and accountability of funders, administrators, and providers.

The campaign's leaders are realistic about what it will take to bring about dramatic shifts in policy. Simply announcing that the mental health field has decided to come together is not going to accomplish much. Concerted opinion research will be vital, as will communication strategies that target key decision makers in Congress and the Administration. The campaign will engage strategists and use poll results to convey important messages. If mental health is to become a national priority, the field has to use all the tools at its disposal.

The campaign has been driven from the start by the assumption that little would happen to the Commission's recommendations without a major push from the advocacy community. This is not to diminish the central role that will be played by SAMHSA in coordinating federal initiatives based on the Commission's recommendations. Rather, it reflects growing sophistication about what it takes to "transform" a system. The transformation envisioned by the Commission is a multilayered process involving consumers, family members, practitioners, bureaucrats, and many others who share a vision of recovery and resilience. Advocates, too, have a critical role in the transformative process. The Campaign for Mental Health Reform is the advocates' attempt to put the lessons they have learned into practice to help achieve the goals of the President's Commission. If the campaign can produce results, mental health advocacy—and the system itself—may truly be transformed.

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Statement From the National Association of State Mental Health Program Directors

Robert W. Glover, Ph.D.

In calling for a transformation of the broad array of services and supports that constitutes the public mental health system, the President's New Freedom Commission on Mental Health challenges policy makers at all levels of government to collaborate in the development of an integrated, effective system of care. The nation's 55 state and territorial mental health agencies, which are represented by the National Association of State Mental Health Program Directors (NASMHPD), acknowledge the critical need for policy makers' leadership in achieving the Commission's vision. As governmental entities whose missions focus primarily on providing services that meet the needs of persons with mental illnesses and their families, state mental health agencies are ideally positioned and eager to serve as agents for reform and progress.

Ironically, many of the challenges we face today are the product of deinstitutionalization, an earlier wave of wholesale system change. In the 1950s, when nearly 600,000 individuals with mental illnesses were confined in state psychiatric hospitals, those hospitals were responsible for providing not only treatment but also housing, food, clothing, education, and social interaction. As people made the transition to community settings, they found a myriad of agencies and programs that were uncoordinated, underfunded, and inadequate to meet the broad range of their needs. At the same time, reforms in major federal programs such as Medicaid, Medicare, and Social Security expanded benefits for people with special needs, including people with mental illnesses. State mental health agency directors have had limited success in translating the promise of these programs into a coordinated system for their constituents.

Today, with fewer than 57,000 state hospital beds across the country, we have a decentralized "system" in which persons with mental illnesses must rely on multiple and uncoordinated service agencies to meet basic human needs with treatments and services that are essential to their recovery. Meanwhile, the capacity of state mental health agencies to finance and manage mental health services has eroded. Over the past 20 years, per capita spending by state mental health agencies has declined by nearly 10 percent (1). Even the explosive growth in Medicaid is deceptive, because greater amounts of state mental health agencies' budgets are diverted to cover the state Medicaid match, leaving fewer dollars to be managed by the agencies themselves.

The Commission's report throws welcome new light on the role of state mental health agencies and their directors. Its call for transformation is a challenge to state mental health directors to reexamine their agencies, rethink their own roles, and reiterate the commitment to recovery in the mission statements they follow. The report challenges them to integrate their agencies' offerings with programs and services that are outside their control and frequently driven by competing priorities and values. It points the way to development of individual care plans that address the full range of needs of child and adult consumers. As state mental health directors, NASMHPD's members must embrace the new reality the Commission projects and take their places as leaders of system transformation in their states.

Would a single, flexible funding stream for all mental health services make the jobs of state mental health agency directors easier? Of course. But even though such a redirection of resources may not be possible in the near term, guaranteeing a comprehensive array of services that appears seamless to the consumer is possible and is essential. The Commission's report provides a historic opportunity for leadership and collaboration that, backed with appropriate resources, must transform the public mental health system to support recovery and hope for millions of Americans with mental illnesses and their families.

Reference

1. Funding Sources and Expenditures of State Mental Health Agencies. Alexandria, Va, National Association of State Mental Health Program Directors, NASMHPD Research Institute, 2001

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Statement From the National Alliance for the Mentally Ill

Richard Birkel, Ph.D.

Below is a brief description of activities under way within the National Alliance for the Mentally Ill (NAMI) that are related to the goals of the Commission's report.

Goal 1. Americans understand that mental health is essential to overall health. NAMI's Campaign for the Mind of America aims to help Americans understand the critical importance of mental health. It also aims to overcome the stigma that surrounds our mental health "system." The NAMI campaign will urge citizens to insist on the development of a world-class mental health system in the United States. Our surveys have shown that although Americans cannot identify what "the mental health system" is and what services and supports are necessary for recovery, they overwhelmingly support increased investments in recovery-focused services once they understand what is possible and necessary. NAMI intends to promote public support for greatly

improved access to mental health services as an essential element of health care reform.

Goal 2. Mental health care is consumer and family driven. NAMI is founded on the belief that being an informed consumer is an essential step in recovery. To bring the best science and practice to consumers and their families, NAMI will improve and significantly expand its signature education programs, which operate in all 50 states and which reach hundreds of thousands of individuals annually. NAMI is also committed to preparing consumers and family members for leadership roles in advocacy, education, and planning in their communities and at the state level. In addition, we are accelerating our work to protect the rights of people with mental illness and their families, beginning with the right to treatment and including the right to work, to have access to decent housing, and to be protected from harm and discrimination. NAMI believes that one of the most egregious violations of rights is the current wave of criminalization of people with mental illness. To combat this calamitous trend, we are launching a new center to work aggressively to keep persons with mental illness out of jails and to get them the treatment they require.

Goal 3. Disparities in mental health services are eliminated. NAMI has made a long-term commitment to diversify its membership, build partnerships with minority leaders and their organizations, and work together to address issues of disparities in care resulting from race, ethnicity, and language. Elimination of disparities is playing an increasingly important role in NAMI's policy agenda, and we are working to identify and support leaders in policy and advocacy from diverse communities.

Goal 4. Early mental health screening, assessment, and referral to services are common practice. NAMI's commitment to the mental health of young children is demonstrated in the creation of our Child and Adolescent Action Center. The center links NAMI state and affiliate organizations together in promoting dissemination of evidence-based practices and advocacy for improved services for children and adolescents, including school-based mental health services and early identification and treatment of disorders. In addition, NAMI will expand its education and support programs for young families with the aim of reaching families in every state.

Goal 5. Excellent mental health care is delivered, and research is accelerated. NAMI supports work along the full continuum, from basic research to ongoing community practice. One program that is of particular importance in ensuring that evidence-based programs are implemented in our communities is the Treatment/Recovery Information and Advocacy Data Base (TRIAD), which is tracking implementation of evidence-based practices in each state. TRIAD provides a mechanism for data-driven advocacy. By tracking state-level investments in such programs as supported employment, assertive community treatment, illness self-management, and family psychosocial education, we will help ensure that resources are targeted to programs that work.

Goal 6. Technology is used to access mental health care and information. NAMI has expanded its communication capability with a new, interactive Web site that provides information, education, and referral services to its visitors. The site, combined with traditional telephone help lines in nearly every state, enables NAMI to assist more than one million individuals each year who are looking for information on services. We also plan to pilot a variety of illness management programs on the Internet in the coming year.

To summarize, NAMI is excited about the possibilities that lie within the vision of transformation described in the New Freedom Commission's report. We believe that it is important to work toward a new, recovery-focused system that is available to all Americans. A critical component of this vision is a commitment to concerted outreach and innovative engagement strategies necessary to reach many individuals who have given up on treatment or have been harmed by treatment and who may be the most ill. We believe this effort is justified on moral grounds alone, but is also sound public health policy. A system that provides access to all Americans is possible and we must not neglect those in greatest need.

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Statement From the National Mental Health Association

Michael Faenza, M.S.S.W.

History is a harsh, unforgiving judge. But I'm confident that when future scholars look back at the work of the New Freedom Commission on Mental Health and its report, *Achieving the Promise: Transforming Mental Health Care in America,* they will conclude that the report represented an important milestone in the history of the mental health movement.

Reckless exaggeration? I don't think so. Admittedly, the Commission has not produced new science. It has not discovered heretofore unknown truths. But it has captured with hard-hitting imagery the tragedy of our society's mental health failures and has

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made those failures and their solutions palpably understandable. The Commission has given us messages that can sear exposed nerves. And it has given us tools to alter the tired paradigm that has stifled major change. Words have power. And powerful things can happen when advisers to the President of the United States indict the public mental health delivery system as a "patchwork relic" that is in a state of "shambles" and decry as a tragedy the failure to make mental health a national priority.

Commission Chair Michael Hogan and his colleagues have brought the ugly truths of society's disgraceful disregard of people with mental illness out of the shadows and to the corridors of power. But before we can realize policy change and needed mental health reform, we must enlarge the conversation. We must reach beyond the op-ed pages and committee hearing rooms. To have real impact, we need a national conversation about mental health. We need to get on "talk radio" and into Presidential debates. We need to get mental illness out of the closet and into living room conversation. We need to talk about mental health and mental illnesses in our places of worship and in our classrooms.

The National Mental Health Association and its more than 340 affiliates nationwide are prepared to take up the gauntlet and work nationally through the Campaign for Mental Health Reform and locally through its public education efforts to ensure that the conversation is relevant to all of our citizenry, not confined to its impact on those with selected diagnoses. Americans must know that our nation's broken mental health system is nothing less than a public health challenge.

By speaking with a unified voice, we can drive home the message that mental health is not just about treatment of the symptoms of mental illness or even just about recovery. It is about public health. It is about all our families and their well-being. Our society has the wealth, the science, and the compassion to respond to mental health risks as vigorously as we respond to SARS, AIDS, West Nile virus, and the range of threats to our "homeland security." The Commission rightly calls for a transformation. All of us have a stake and a role in bringing that transformation about. Together we will make mental health a national priority.

Statement From the Bazelon Center for Mental Health Law

Robert Bernstein, Ph.D.

The Bazelon Center for Mental Health Law is gratified that the President's New Freedom Commission declares that recovery from mental illness is the goal of the public mental health system. This is the first time that such a goal has been articulated in any federal policy document.

So far, systems have been geared primarily toward crisis response and have furnished little or no psychiatric rehabilitation or supports for life in the community, such as integrated housing. Establishing recovery as the benchmark for public mental health services represents a major step toward the kind of profound change we envision. Just as positive, and just as novel, is the New Freedom Commission's road map for person-centered services, in which consumers and the families of children with mental health needs play a major role both in developing a care plan and in managing the funding of the chosen services and supports.

The Commission acknowledges the corrosive fragmentation of current programs that so often results from conflicting federal rules and program goals. If these disparities are addressed as a result of the Commission's work, states will be better able to follow the Commission's recommendations for creativity and efficiency in coordinating the use of federal, state, and local funds to overcome barriers that now stand between mental health consumers and recovery.

Such coordination is essential to fulfill mental health consumers' right to community integration, affirmed by the Supreme Court's *Olmstead* decision. We welcome the Commission's reemphasis of President Bush's commitment to that goal. Public mental health systems must quickly end their reliance on costly, unnecessary, and illegal segregation—of adults, in hospitals, nursing homes, and settings such as the "adult homes" that have been the focus of a recent public scandal, and of children, in residential treatment centers and juvenile detention facilities.

A reformed system will need resources to do the job. After reorienting systems to make them more efficient, flexible, and responsive, it will be necessary to reverse decades of underfunding and of mental health budgeting that continually falls behind inflation.

But dollars alone, no matter how many, are not enough. A focus on recovery will require states, localities, and the federal government to rethink the organization of their programs and reorient the people with mental illnesses who are served. The next test will be whether states and localities see the Commission's report as a guide for reengineering their own systems and whether the federal agencies whose primary responsibility is not mental health take these recommendations to heart.

The Bazelon Center has developed a model state law that would create an entitlement to recovery-oriented services and give mental health care consumers the right to select the services and supports they find most helpful. We urge Congress, the Administration, and the states to develop such policy approaches to support the Commission's new vision and then fund a reformed mental health system that can offer meaningful opportunities for recovery.

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