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Executive Summary

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PRINCIPLED MENTAL HEALTH SYSTEM REFORM

TIMOTHY A. KELLY, PH.D.

An estimated 5.6 million Americans suffer from severe mental illness. It strikes without regard to age, gender, race, education, socioeconomic status, culture, or ideology. In many cases it brings suffering not only to the individual but also to family and friends. Depression, which causes many of the 30,000 suicides in America each year, especially targets the elderly. Schizophrenia tragically afflicts some of America's best and brightest adolescents. Persons with mental illness deserve compassionate support, but are often met with fear and stigma. They need effective treatment, but are too often offered ineffective care, if any at all.

The economic costs of mental illness are staggering. America spends over $69 billion yearly on direct treatment costs. Virginia is a case in point: It spends over $1 billion for publicly funded psychiatric care each year; per-bed-year costs of hospitalization run between $108,000 and $175,000. Yet there are long waiting lists for community services, and many persons with severe mental illness are caught in a vicious circle. They enter a psychiatric hospital for treatment, are discharged back to their home community with no effective follow-up care, and end up homeless or back in the hospital. In addition, it is not unusual for those with private insurance to end up in public care once their limited coverage is exhausted.

Current mental health policy tends to support the status quo system regardless of the effectiveness of services, wasting precious resources that could be redirected to help those who are not receiving needed care. Worse, current policies doom many persons with mental illness, the self-termed "survivors" of the defective service system, to lives of marginal functionality and dependency when, with effective treatment and more compassionate care, they would be capable of productive independent living.

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This must not continue. America has the compassion, resources, and treatments to care effectively for its citizens who suffer from severe mental illness. Federal and state policymakers must make comprehensive reforms in mental health care that are based on seven key principles: treatment quality, treatment access, consumer choice, personal independence and productivity, self- and family participation, provider accountability, and government responsibility for treat-

ments that improve the quality of life for persons with mental illness. A system based on these principles would enable individuals and their families to manage the challenges and weather the heartbreaks of mental illness much more effectively.

The steps the federal government should take to implement this system are:

- **Block grant** Medicaid to the states and remove Medicaid restrictions so states have the flexibility they need to pilot new programs and fund mental health system reforms.
- **Encourage** greater creativity with federal funds that are not block granted and reward pilot programs that lead to improvements in the quality of care.
- **Coordinate** the many federal agencies that are involved with mental health to overcome their fragmentation and to refocus them on system reform.
- **Develop** standardized measures of performance and outcomes for providers so states can develop more effective forms of treatment based on actual results.
- **Increase** funding for developing new mental health treatments, and for testing treatment effectiveness with standardized measures, so that policymakers will have scientific data on which to base their decisions.
- **Define** severe and persistent mental illness so that resources can be focused on those with severe needs on a priority basis.
- **Change** the tax structure for health insurance to allow tax deductions for the cost of employee-owned portable insurance in order to maximize coverage options and choice.

At the same time, the states should:

- **Close** unneeded psychiatric facilities and retrain staff for community service.
- **Fund** new community services with the savings achieved from facility closures.
- **Hold** mental health providers accountable using standardized outcome measures.
- **Break** the state monopoly on public mental health services.
- **Evaluate** prevention and early intervention programs and offer their services to parents, schools, families, providers, hospitals, and the community.
- **Promote** comparable insurance coverage for physical and mental health benefits.
- **Establish** safeguarded outpatient commitment as an alternative to homelessness or hospitalization.

Reforms that incorporate these recommendations would ensure America develops a comprehensive mental health care system that truly meets the needs of persons with mental illness, providing compassionate and effective treatment and helping many return to productive lives. Federal and state policymakers must resist the temptation to make only slight modifications to the status quo and declare victory. The current system is broken and can only be fixed with far-reaching reforms that will not come easily.

It is not compassionate to fund failure. Principled mental health reform calls for raising expectations, measuring progress, rooting out failures, and insisting that America can do better for these, its most vulnerable citizens. America has the resources, compassion, and effective treatments necessary to make this happen, and the time to act is now.

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An estimated 5.6 million Americans suffer from severe mental illness, which often profoundly affects both their lives and those of their families.[1] Mental illness strikes without regard to age, gender, race, education, socioeconomic status, culture, or ideology. Depression, which causes many of the 30,000 suicides in America each year, especially targets the elderly. Even the young are not immune—schizophrenia tragically afflicts some of America's best and brightest adolescents. For many, mental illness is a life-long burden they must bear alone. They deserve compassionate support, but too often are met with fear and stigma. They need effective treatment, but too often are offered ineffective care, if any at all. Some wander the streets, speaking to unseen specters. Some languish in the back wards of psychiatric hospitals or in nursing homes. Others are locked away in jails and prisons. But most live with their families and work in their communities, carrying their anguish privately. They often refer to themselves as "survivors,"[2] not just of mental illness, but of a mental health care system that needs genuine reform.

The economic costs of mental illness are staggering. America spends over $69 billion on direct treatment costs each year.[3] The Commonwealth of Virginia, for example, spends over $1 billion each year[4] on publicly funded psychiatric care alone (not including private care), paying between $108,000 and $175,000 per hospital

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1. "Health Care Reform for Americans with Severe Mental Illnesses: Report of the National Advisory Mental Health Council," *American Journal of Psychiatry,* Vol. 150 (1993), pp. 1447–1465. Note that less severe forms of mental illness may affect up to one in five Americans, according to the Surgeon General. See U.S. Department of Health and Human Services, "Mental Health: A Report of the Surgeon General," 1999.
2. Many of those with severe mental illness prefer to be referred to as either a "survivor" of the mental health system, a "consumer" of mental health services, or as a "person with mental illness," as opposed to a "patient" or "the mentally ill." Accordingly, the preferred terms will be used interchangeably throughout this paper.
3. U.S. Department of Health and Human Services, "Mental Health: A Report of the Surgeon General."

bed-year for adult inpatient care.[5] Despite such vast dedicated resources, in most states there are long waiting lists for community services. Many "survivors" with severe and persistent mental illness are caught in a vicious circle: They enter a state or private psychiatric hospital for treatment and stabilization, are later discharged to the home community with no effective follow-up care, only to deteriorate and end up homeless or back in the hospital. It is also not unusual for persons with mental illness who have private insurance to begin private treatment but eventually end up in public care once their limited coverage is exhausted.

Current mental health policy tends to support the status quo, funding services regardless of effectiveness and wasting precious resources that could be redirected to treat those who need care the most or who are not receiving care at all. Moreover, current policies doom many "survivors" to lives of marginal functionality and needless dependency, even though they would be capable of productive independent living if they were to receive effective and compassionate care.

This must not continue. America has the compassion, resources, and treatments to care effectively for its citizens who suffer from severe mental illness. The time is right for federal and state policymakers to make sweeping comprehensive reforms to the current system, not by throwing more resources blindly at failed approaches or pleasing special interest groups, but by providing compassionate and effective treatment services and holding the agencies involved accountable for quality care.

Federal and state policymakers must establish a framework for comprehensive system reform that is based on the following seven principles:

1. Treatment Quality—Improving mental health care quality by measuring clinical outcomes and funding only those treatments that work.
2. Treatment Access—Improving access by encouraging public and private insurers to recognize the importance of mental health care and encouraging comparable physical and mental health coverage to consumers.[6]
3. Consumer Choice—Increasing treatment options by allowing mental health consumers to choose among competing providers and treatments, and by instituting employee insurance ownership and portability.
4. Personal Independence and Productivity—Designing services to help persons with mental illness find fulfillment through real work, a real home, and real relationships to improve their independence and productivity in the community.
5. Self- and Family Participation—Allowing persons receiving care, and their families, to be active participants in the development of policies regarding services and in evaluating the effectiveness of their providers and treatments.
6. Provider Accountability—Replacing the current monopolistic public mental health system with open-market competition among providers, with contract renewal dependent upon performance, to improve the quality of care.
7. Government Responsibility—Ensuring that the quality of life for persons with mental illness dramatically improves as a direct result of their policies.

Reforming the current mental health system using these principles would enable individuals and their families to manage the challenges and weather the heartbreaks of mental illness much more effectively.

To implement such a system, the federal government should consider the following steps: block granting Medicaid to the states; encouraging states

4. Testimony presented by subcommittee staff to Virginia's HJR–240 Joint Subcommittee Studying the Future Delivery of Publicly Funded Mental Health, Mental Retardation and Substance Abuse Services, June 1996.
5. State of Virginia, Hammond Commission Interim Report on Community Services and Inpatient Care, December 1998.
6. As a mandate, this concept is sometimes referred to as "parity" in mental health insurance.

to innovate with federal funds not block granted in order to test the effectiveness of new treatment approaches; coordinating the efforts of federal agencies involved with mental health; developing standardized measures of performance and outcomes; increasing funding for treatment development and research; defining severe and persistent mental illness so that resources can be focused on those with severe needs; and changing the federal tax structure of health insurance to maximize coverage options and increase consumer choice.

At the same time, state governments should take steps to: close unneeded psychiatric facilities; fund new community services; hold mental health providers accountable; break the state monopoly on public mental health services; evaluate prevention and early intervention programs; promote comparable insurance coverage for mental and physical health benefits; and establish safeguarded outpatient commitment as a viable alternative to homelessness and hospitalization.

These reforms would enable policymakers at the federal and state level to create a comprehensive mental health care system that truly meets the needs of persons with mental illness compassionately and effectively, and would help many of them return to productive lives in their own community. Legislators, however, must resist the temptation to make only slight modifications to the status quo and then declare victory. The current system is broken, and can only be fixed with far-reaching reforms that will not come easily.

WHAT'S WRONG WITH MENTAL HEALTH POLICY

Mental health policies today are far better than those of decades past when "treatment" frequently meant criminalizing or institutionalizing persons with mental illness. With the discovery of anti-psychotic medications in the 1950s, deinstitutionalization of persons with mental illness became possible, and many for the first time were able to be discharged from psychiatric institutions. Since that time the community mental health system gradually evolved, intended to provide support and services in the home community.

In both cases—deinstitutionalization and community mental health care—the fundamental policy concepts were correct. It is best for institutionalization to be rare and short-term, and it is best for communities to care for people close to home. Unfortunately, viable goals and good intentions did not lead to well-designed policies. The results have more often been rigid federal guidelines and monopolistic state service delivery systems that inadvertently promoted dependency and homelessness, rather than independence and productivity.

What Went Wrong?

The system did not achieve its intended result for several reasons:

- **Deinstitutionalization failed.** Despite the availability of anti-psychotic medications and the noble desire to treat people in their home communities, homeless persons with severe mental illness have become a sadly common feature of the American landscape. According to Dr. E. Fuller Torrey, an expert on schizophrenia, "hundreds of thousands of vulnerable Americans are eking out a pitiful existence on city streets . . . because of the misguided efforts of civil rights advocates to keep the severely ill out of hospitals and out of treatment." Moreover, state laws, some driven by challenges from the American Civil Liberties Union (ACLU), "prevent treating individuals until they become dangerous."[7] In other words, current policies make it all too easy for persons with severe mental illness to receive little or no treatment after they have been discharged from a psychiatric hospital. Often, effective treat-

7. "Deinstitutionalization Hasn't Worked," *The Washington Post*, July 7, 1999; see also E. Fuller Torrey, *Nowhere to Go: The Tragic Odyssey of the Homeless Mentally Ill* (New York: Harper & Row, 1988). For a general discussion of the legal issues surrounding mental illness, see E. Fuller Torrey, *Out of the Shadows: Confronting America's Mental Illness Crisis* (New York: John Wiley & Sons, Inc., 1997).

ment is not available; sometimes the person may not realize the need for treatment and will refuse care. Regardless of the reason, however, the result is untreated mental illness.

- Legal actions misdirect "improvements." The U.S. Department of Justice (DOJ) has brought costly legal action against many state mental health agencies for failing to place hospitalized patients in the community when appropriate. Additionally, a Supreme Court decision (*Olmstead* v. *L.C.*) was handed down on June 22, 1999, which ruled that unnecessary hospitalization of persons with mental illness constitutes a violation of their rights under the Americans With Disabilities Act. States are, therefore, becoming ever more vulnerable to legal actions, especially if effective and accountable community-based reforms are not forthcoming. Many states respond to this threat by attempting to expand and reform community care, but often this is done without the benefit of tested and comprehensive policy recommendations to guide them. For example, community funds may be increased to address "unmet needs,"[8] but without a requirement that treatment effectiveness be evaluated. As a result, more people receive costly and ineffective services, but the need for better clinical outcomes remains unaddressed.

- Mental health care costs continue to increase. Both private and public insurers (such as Medicaid) are failing in their attempts to hold down mental health care costs. Demand for services is rising, and debate rages as to whether additional categories of mental illness—such as marriage problems and bereavement—should be covered. Since the diagnosis and treatment of mental illness is still far from an exact science, insurers find that it is difficult to predict policy effects on their insured. For example, managed care technologies have been applied with the expectation that a significant one-time savings will be achieved when moving from traditional fee-for-service to a managed network of providers, as well as ongoing savings realized from increased efficiencies; this has been the pattern with physical health care. But results to date suggest that, in the arena of mental health, neither benefit can be counted on. As one case in point, Tennessee found it to be extremely difficult to develop a successful managed mental health care system for Medicaid recipients (in its system known as TennCare) and has had to experiment with several management models. The reason for the poor results may be that most managed care savings are generated by reducing overuse of hospital beds, specialist care, and emergency care—none of which can be accomplished without comprehensive mental health system reform.

Response to Policy Failures

These problems heighten frustration and increase calls for Washington and state legislators to do something. Americans with mental illness, as well as their families, are no longer content simply to receive whatever care or coverage is offered. This is seen most clearly in the rise over the past decade of mental health consumer and advocacy groups such as the National Alliance for the Mentally Ill (NAMI). NAMI and other such organizations are becoming increasingly active in lobbying at both the federal and state levels, pushing for improved quality of care and access and attempting to eradicate the stigma of mental illness. They are demanding greater participation in all levels of the policy development process.

Consequently, federal and state legislators are being pressured to address a growing number of challenging mental health policy issues without an adequate knowledge of the problems or a comprehensive policy framework to guide them. On the federal level, for example, Congress is considering a number of measures:

- The 1996 Mental Health Parity Act requires insurance companies to offer the same lifetime

8. This term is commonly used to refer to social needs relevant to government programs that are not covered by existing service capacities.

and annual dollar limits for physical and mental services. Congress is now considering two bills (S. 796 and H.R. 2593) to broaden the parity legislation. The main difference between these bills involves the definition of who would be considered eligible for coverage. The Senate bill would apply only to severe mental illness; the House bill is much broader.

- The Work Incentives Improvement Act of 1999 (H.R. 1180), among other things, provides healthcare and other supports for persons with mental illness who attempt to reenter the job market. The bill passed the Senate and House last fall, and it was signed by the President on December 17, 1999.
- In November 1999, Congress appointed conferees for the managed care Patient's Bill of Rights Plus Act (H.R. 2990), which would establish such basic "rights" as the ability to use "off-formulary" medications. The President threatens to veto the bill for not going far enough.
- The need to limit a psychiatric hospital's use of seclusion and restraints for hospitalized persons with mental illness is being considered in several bills (S. 736, S. 750, and H.R. 1313).
- A bill under consideration in the Senate (S. 976) would improve federally funded youth drug and mental health services. It calls for focusing on community-based services and improving effectiveness, flexibility, and accountability.
- The House is considering a bill (H.R. 2576) that would establish a new substance abuse agency by consolidating and reorganizing several of the overlapping federal agencies working in that area.
- The Youth Suicide and Violence Research Act (S. 1555) would increase funding for research to study the increasingly common and tragic incidents of youth suicide and violence.
- The Senior's Mental Health Access Improvement Act (H.R. 2945) would include marriage and family therapy in Medicare coverage.

Such policy issues and questions are coming before legislators not only on Capitol Hill but in every state capital in the nation. Public debate on these matters is sporadic at best and usually flares up around a single issue that captures the media's attention for a short time. What is needed, however, is a more careful, comprehensive, and deliberative process that takes into account a reform of the whole mental health system, not just one of its components.

SEVEN PRINCIPLES FOR REFORM

For mental health system reform to be comprehensive and enduring, it must be based on the right principles. The following seven key principles, which have been formulated from a review of the relevant literature and over 20 years of service in the mental health arena,[9] are intended to provide a solid basis for comprehensive reform of the current mental health system. Such reform would ensure compassionate and effective care for persons with mental illness and their families.

Principle #1: Increase quality of care by measuring outcomes and funding only those treatments that work; any savings realized should be reinvested in creative and proven state-of-the-art services. All too often, mental health professionals intervene in the lives of persons with mental illness without making every effort to measure and document the outcome of their intervention. One unintended outcome is homelessness, as the vicious circle of institutionalization and discharge without effective follow-up described above points out. The question of which treatment works best for each individual should be continually raised and scientifically addressed throughout the service delivery system. Scientifically tested measures have been piloted in the real world of service delivery and are available.[10] Mental health care

9. The author has worked in the mental health field as a provider, university researcher, assistant professor of psychology, and state Commissioner.

will improve when it is driven by results—when it becomes evidence-based.

Principle #2: Increase access by moving toward mental health coverage—for people with severe mental illness—that is comparable to physical health coverage. Public and private insurers should be motivated to offer comparable physical and mental health coverage. Policymakers should make sure they recognize the critical importance to society of effective mental health services, as opposed to just physical health care. They must also recognize the growing market for insurance products that cover legitimate needs, including treatment for severe mental illness. It is critical, of course, that increased coverage does not simply fund the expansion of the status quo.

Principle #3: Increase consumer choice by restructuring tax law and increasing treatment options. Tax law should be revised to allow deductions for employee-owned portable insurance policies. This change would make insurance products more flexible—a market-driven commodity owned by those who pay for them rather than their employers. Such products should offer mental health coverage and choice among competitive providers.

Principle #4: Increase independence and productivity by ensuring that treatment programs help persons with mental illness find fulfillment through real work, a real home, and real relationships. The goal of all interventions must be to enable persons with mental illness to live and function as independent and valued members of their communities to the fullest, most realistic extent possible. The somewhat controversial but important concept of outpatient commitment is relevant here, because it would provide a legal framework within which community treatment can be assured. Far better to be in the home community through safeguarded outpatient commitment than to be on the streets or hospitalized.

Principle #5. Increase consumer and family participation in the development of service policies, and in the evaluation of treatment and provider effectiveness. Policymakers and insurers must no longer assume that the policies they develop and implement autocratically will be accepted automatically by those covered. At a reasonable point in the deliberative process, it is necessary to include those individuals and their families whose lives will be affected by the decisions reached. In addition, consumers of mental health services must be given an opportunity to rate the quality and effectiveness of the care they receive. This information, in aggregate form, would enable legislators and policymakers to identify and support the most effective programs.

Principle #6. Increase provider accountability by replacing the monopolistic public mental health system with open competition. This would require opening the public sector to private providers, linking contract renewal with provider performance, and regularly publishing both public and private provider performance assessments. Such accountability would dramatically improve the quality of care, since that which is measured tends to improve.

Principle #7. Increase federal and state government responsibility for improving the quality of life for persons with mental illness through their mental health reforms. Compassionate and effective mental health reform should yield dramatic improvements in the lives of those receiving care. Standardized outcome data would provide comparative information on how well each state or program is doing in that regard. State and federal agencies should be held accountable for program results and pay a price if significant yearly improvements are not forthcoming. On the federal side, effort must be made to bring coordination and coherence to the numerous agencies that oversee various components of mental health research, policy development, funding, laws, and

10. See, for example, W. Lutz, Z. Martinovich, and K. I. Howard, "Patient Profiling: An Application of Random Coefficient Regression Models to Depicting the Response of a Patient to Outpatient Psychotherapy," *Journal of Consulting and Clinical Psychology,* Vol. 67 (1999), pp. 571–577; T. A. Kelly, "A Wake Up Call: The Experience of a Mental Health Commissioner in Times of Change," *Professional Psychology: Research and Practice*, Vol. 28 (1997), pp. 317–322.

programs.[11] These agencies should work together formally and creatively to achieve the same goal—principled mental health system reform.

On the state side, policymakers should become more proactive in legislating comprehensive reform guidelines for public and private providers of mental health services. The current piecemeal approach is wasteful, ineffective, and will not result in mental health system reform. Adding a few programs to the status quo will not dramatically improve the lives of persons with mental illness.

WHAT TO DO

Guided by these principles, it is possible to develop strategic recommendations for federal and state legislators to enact comprehensive reform of the mental health system. Federal and state laws and regulations set the parameters for mental health services across the country. When all is said and done, improving care and creating new opportunities to help persons with mental illness will benefit not only those individuals, but their families and communities as well.

Federal Reforms. Specifically, the federal government should:

1. **Block grant Medicaid to the states.** Medicaid restrictions should be removed in order to give states the flexibility they need to develop and fund new mental health system reforms. Currently, Medicaid funds come back to the states with strings attached that tend to stifle innovation and promote the current rigid service delivery system. For example, most state Medicaid plans cover acute care hospitalization for persons with schizophrenia, but not assertive community care that would allow them to live successfully at home.[12] As a result, patients who could have gone home remain hospitalized longer than needed. They have coverage for expensive inpatient services, but not for more effective and less costly community care.[13] States should be trusted to spend their own money in a more effective and compassionate manner.

2. **Encourage greater creativity with any federal funds that are not block granted to the states.** Federal funds should be made available to the states for pilot programs to test creative new treatment options, such as telepsychiatry and faith-based treatment programs. Seed money should be provided with the stipulation that effectiveness measures must be built into all pilot programs, and that demonstrated efficacy using standardized measures is required for continued funding. Since that which is measured tends to improve, the ongoing measurement of clinical outcomes will lead to continual improvement in the quality of mental health care in old and new services alike.

3. **Coordinate the many federal agencies involved with mental health.** Congress should work with the executive branch to bring coordination and focus to the efforts of the federal agencies that oversee various components of mental health research, policy development, funding, laws, and programs. (See sidebar p. 9.) If their efforts were cooperatively oriented toward the single goal of achieving principled mental health system reform, much greater progress would be made. Instead, their uncoordinated efforts sometimes support and other times hinder reform. For instance, a recent report found that the National Institute for Mental Health (NIMH) dedicates only 36 percent of its

11. For example, National Institute of Mental Health, Substance Abuse and Mental Health Services Administration, National Institute of Alcohol and Alcohol Addiction, National Institute on Drug Abuse, Health Care Financing Administration, Office of Personnel Management, Social Security Administration, and the Departments of Housing and Urban Development, Justice, Labor, and Veterans Affairs.

12. See the discussion of Program for Assertive Community Treatment below.

13. The Health Care Financing Administration finally began promoting assertive community treatment to state Medicaid directors in June 1999, although it has been available for about 25 years.

research funds to support basic and clinical research on severe mental illness.[14] An interagency task force, or perhaps a short-term commission, could be created to recommend how to overcome this fragmentation of mental health agencies and how to coordinate their policies in the future.

4. **Develop standardized measures of performance and outcomes.** Congress should require the NIMH to develop a scientifically derived catalogue of standardized performance and outcome measures that are appropriate for various aspects of mental health service delivery and treatment. States should be encouraged to require providers—both public and private—to use these measures so that their outcomes may be comparatively evaluated, not only within each state but nationally as well. Much progress has been made toward developing research-based measurements for clinical outcomes.[15] However, a set of broadly supported, standardized mental health outcome measures needs to be developed and universally applied. The Agency for Health Care Planning and Research (AHCPR) has developed similar outcome measurement tools for other medical treatments, including some mental health treatments. The NIMH, perhaps in conjunction with the AHCPR, is well-positioned to accomplish this task and to offer (not mandate) the product developed to the states. States interested in mental health reforms will want to adopt these measures in order to have access to valid data that will allow them to evaluate progress.

5. **Increase funding for research on mental health treatment and outcomes.** Congress should increase funding for NIMH research on promising new mental health treatment approaches, and on the comparative effectiveness of current treatments. The NIMH should target funding toward ongoing national research on the effectiveness of specific treatments (using standardized measures) so that policymakers will have scientific, comparative data available on which to base their decisions. New medications developed by pharmaceutical companies and new behavioral treatment approaches should be subjected to clinical trials as quickly as possible so that new products reach the market promptly.[16] In this way, mental health policymakers would have reliable information on a range of available and effective services from which to design comprehensive reforms. Over time, this approach would lead to proven mental health treatments, which would be a welcome replacement for the status quo.

6. **Define severe and persistent mental illness.** Congress should require the NIMH to set the standard for a diagnosis of severe and persistent mental illness, drawing on the work of the National Advisory Mental Health Council. Currently, severe diagnoses such as schizophrenia, bipolar disorder, major depression, and obsessive-compulsive disorder compete with far less threatening diagnoses for coverage. Sound research would enable the NIMH to determine where the line should be drawn between severe and persistent mental illness and other diagnoses so that limited resources could be targeted, on a priority basis, to help those with severe needs. Of course, less severe needs are also important and worthy of attention, but they should be classified separately. Some, such as bereavement and marital problems, should perhaps be classified as "life problems" and thus not draw down available coverage for persons with severe and persistent mental illness. Otherwise, mental health services will be spread too thinly over an ever-expanding list of social needs. Reforming

14. "The Failure of the National Institute of Mental Health to Do Sufficient Research on Severe Mental Illness," report issued by the Stanley Foundation Research Programs and the National Alliance for the Mentally Ill, 1999.

15. See Lutz *et al.*, "Patient Profiling." See also Kelly, "A Wake Up Call."

16. The Food and Drug Administration tests pharmaceuticals for safety and basic effectiveness, but the complex interaction of medications and behavioral therapies for various diagnoses falls to the NIMH.

mental health care can dramatically improve the quality of life for persons with severe mental illness, but it cannot solve all of life's problems.

7. **Change the tax structure for insurance.** Congress should enact refundable tax credits for employee-owned health coverage, as well as for supplemental and portable health benefits that employees take with them when they change jobs. This would lead to more flexible and responsive insurance policies that are owned and controlled by consumers rather than their employers. It would lead to increased coverage and greater choice for consumers, and would make it easier for families that desire policies with comprehensive mental health coverage. Thus, the market would accomplish what government is often tempted to mandate—better coverage for more people. This approach could apply to Medicaid services as well; Medicaid recipients could choose private plans with the premiums covered by Medicaid vouchers, if they wished. More choice leads to more competition among providers, which in turn improves the quality of care.

State Reforms. At the same time, state governments should:

1. **Close unneeded psychiatric facilities.** Legislators in over-hospitalized states must summon the political will to close unneeded psychiatric facilities and retrain their staffs for community care. The savings realized from this effort should be reinvested in state-of-the-art community health care services. It is simply not economically feasible to maintain unneeded psychiatric hospitals and still finance community-based reforms. Moreover, the more effective and compassionate option is to provide services in the home community to the fullest extent possible. Although inpatient care will always be necessary for some persons, many states still have too many beds dedicated to psychiatric care. To avoid repeating past failures with deinstitutionalization, however, closing facilities must be done only in conjunction with the development of effective community services.

2. **Fund new community services.** State legislators should dedicate the savings they realize by closing unneeded facilities, and appropriate additional funding as needed, to develop creative and accountable community care that provides whatever a person with severe mental illness needs to succeed in the home community. Many promising innovative community services are now available, and more are being developed. (See sidebar on p. 10 for examples.)

3. **Make mental health providers more accountable.** State legislators must hold all mental health providers accountable for the outcome of their care by requiring their agencies to

Some of the Federal Agencies that Deal with Mental Health

National Institute on Drug Abuse

Substance Abuse and Mental Health Services Administration

National Institute of Alcohol and Alcohol Addiction

National Institute of Mental Health

Office of Personnel and Management

Social Security Administration

Agency for Health Care Policy and Research

National Institute on Aging

National Institute of Neurological Disorders and Stroke

Department of Housing and Urban Development

Department of Justice

Department of Labor

Department of Veterans Affairs

Health Care Financing Administration

Examples of Innovative Community Services

The Program for Assertive Community Treatment (PACT). Psychiatric hospital workers created PACT after seeing many of their patients return to the hospital after release because of poor follow-up care in the community. Under PACT, hospital-level teams of mental health professionals are put on the street to work with persons with severe mental illness on a 24-hour, seven-day-a-week basis. PACT strives to provide top-quality clinical and practical resources to a community and to do whatever it takes to help recipients succeed. This commitment could mean monitoring medications at midnight, helping someone overcome a problem at work, or providing psychotherapy in the home. Research demonstrates that this program is both clinically effective and cost effective, especially for those who are the most treatment resistant.

Atypical Medications. New medications are available for treating many mental illness diagnoses, including schizophrenia. For some, these medications can have an almost miraculous effect, allowing those who have been hospitalized for years to return home and function well. They are more costly than typical medications, but much less costly than inpatient care.

Telepsychiatry. Like telemedicine, teleconferencing technology allows a patient to link up with a doctor or treatment team that may be too far away to visit in person. It is especially useful for psychiatric evaluations of persons in rural environments who would have to travel long distances for evaluation or care. It also has been used to avoid prolonged hospitalizations; patients are sent home with a laptop computer equipped with video camera. The technology allows them to check in as needed with their psychologist or psychiatrist from their homes.

Clubhouses and Drop-In Centers. A "clubhouse" staffed by professionals and a "drop-in center" staffed by volunteers are treatment options that offer much-needed social support for persons with severe mental illness. They vary greatly in their effectiveness, depending on their focus and on how well they are managed and funded. Centers that provide more than social support, including comprehensive employment services, seem to be most effective in helping persons with mental illness function better in their home communities.

Faith-Based Programs. There is a growing recognition of the value and effectiveness of faith-based programs for some persons with severe mental illness. For that reason, the federal government recently began to loosen restrictions on funding such programs. These programs provide a potentially huge and relatively untapped resource that communities can use as they move ahead with mental health reforms. People of faith and persons with mental illness could be linked on a volunteer basis for friendship and support, or critical services (such as residential drug rehabilitation or PACT services) could be contracted out to a faith-based organization such as the Salvation Army.

institute comprehensive measurements of outcomes and to collect and publish their findings regularly. These measures should include the assessments of clinicians, consumers, families, employers, and schools, as appropriate, regarding both clinical outcomes (such as symptom reduction) and lifestyle outcomes (such as the ability to hold a job). The data would be aggregated by agency and contain no individual identifying information to protect privacy. It would be used to inform consumers and their families about the quality of the care provided and to guide policy decisions concerning contract renewal and funding allocations. Of course, the data would have to be interpreted carefully, taking into account any factors beyond the provider's control and screening out any attempts to "game" the system.

4. **Break the state monopoly on public mental health services.** State legislators should help develop a competitive public mental health system by directing their mental health agency

to contract for facility and community care in the open market. The agency should be directed to renew contracts based on carefully interpreted provider performance and efficiency—not on "units of service delivered," a euphemism for the number of contacts made without regard to outcome. States also should consider creating a Medicaid voucher system that would allow consumers to select care from either the public or private sector. In this way, the mediocrity of care inherent in a monopolistic system would be replaced with the higher quality of care that results from market competition.

5. **Evaluate prevention and early intervention programs.** State legislators should study the extent to which their mental health agency provides useful information and creative referral options to schools, healthcare professionals, public safety officials, faith-based organizations, and communities. Agencies should be required to demonstrate that early intervention services are available and effective. Accurately diagnosing a very young child with autism and offering the family support for home care, for example, would meet the family's needs and may well avoid hospitalization later on. But it is not enough simply to establish that prevention and early intervention programs exist. Program effectiveness must be monitored continually to document the extent to which it is helping and to guide future decisions on funding and program development.

6. **Promote comparable insurance coverage for mental health.** State legislators should motivate insurance companies in their states to recognize the critical importance of mental health care, and to offer policies with comparable coverage for mental health benefits. Employee-owned policies would facilitate this process by creating a market for such coverage. After all, families that already struggle with the effects of severe mental illness should not have to struggle financially as well due to poor coverage. There are some indications that this approach does not significantly increase overall health care costs (for example, Ohio found that offering such comparable coverage for state employees only minimally increased costs). However, it is important to note that providing increased coverage for mental health services without comprehensively reforming the service system would likely benefit providers more than consumers.

7. **Establish outpatient commitment.** States should update current law or enact new laws that establish safeguarded outpatient commitment as a viable alternative to the re-hospitalization-homelessness cycle. However, an adequate network of effective community supports and services must first be put in place for outpatient commitment to be successful. With such services in place, outpatient community commitment offers protection for people who would otherwise be at high risk for homelessness. It establishes a legal framework wherein persons with severe and persistent mental illness may be discharged to the home community with the imperative to follow treatment. If they do not, their doctor has the option of re-hospitalizing them before they become homeless or are otherwise at risk of harm. Since this would limit a person's right to refuse treatment, that right must be safeguarded with an effective review and appeals process. With such safeguards and adequate community services in place, outpatient commitment would help break the vicious circle of hospitalization and homelessness that often results from treatment disruption.

Improvements and Opportunities

With these mental health system reforms in place at both the federal and state levels, persons with mental illness and their families would find care dramatically improved and would have greater opportunity to participate in the system. They could reasonably expect a responsive and compassionate system of mental health treatment options that are based on proven results.

The benefits to these individuals and their families would include:

- **Participation in treatment choices.** They could expect to have a voice in selecting the provider and shaping actual treatment (such as frequency of therapy, choice of medication, or faith-based versus traditional care).

- **Participation in treatment outcome measurement.** They could expect to report on how effective or ineffective the specific treatment was.

- **Participation in service and provider evaluation.** They could expect to be asked to rate the performance of the provider or service organization.

- **Participation in policy deliberation.** They could expect reasonable representation at the policy development table in both the public and private sector.

- **Real jobs in the home community.** They could expect treatments, services, and supports which are designed to enable the persons treated to find and hold real jobs in their home community.

CONCLUSION

This past year has seen two milestones in mental health policy: the first White House Conference on Mental Health and the first Surgeon General's Report on Mental Health. Federal policymakers are beginning to address the complex but critically important policy issue of mental health system reform. The question is whether they will address it in a fragmented manner, perhaps increasing government regulation and price controls, or in a comprehensive manner based on clear reform principles. The former strategy will expand mental health bureaucracies but lead to little real change. If the lives of persons with severe mental illness and their families are to improve dramatically, then dramatic action is required—with principled, system-wide mental health reform.

The current problem is not that nothing is being done. For example, the Commonwealth of Virginia is moving ahead with a pilot project to develop and incorporate performance and outcome measures for the state's mental health care system. The state of Texas is piloting new ways to contract out for community service and has led the way in developing outcome measures for psychiatric facilities. The state of New York recently approved innovative outpatient commitment legislation. These steps are moving in the right direction; but at the same time, there is often fierce opposition to other critical changes, such as closing unneeded facilities and reinvesting in community services, or allowing for competition and outcome-based accountability. Without these critical components, mental health system reform will occur sporadically at best. Sacred cows cannot be tolerated alongside genuine reform efforts, for they doom persons with severe mental illness to second-rate care.

Much has been written about the need to overcome the stigma and fear associated with mental illness, especially in light of highly publicized cases of violence and homelessness of persons who refuse or cannot find treatment. Genuine mental health system reform would address both of these concerns far more effectively than would an advertising campaign. The public's fear and unease will subside as greater numbers of persons with severe mental illness become productive citizens in their home communities, supported by compassionate and effective care.

It is not compassionate to fund failure. Principled mental health reform calls for raising expectations, measuring progress, rooting out failures, and insisting that America can do better for some of its most vulnerable citizens—persons with severe mental illness. America has the compassion, resources, and treatments to make this happen, and the time to act is now.

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