

# State Advocacy Update

## Advocates Offer Promising Practices in *Olmstead* Planning

NMHA recently convened MHA advocates involved in their states' *Olmstead* planning to share success stories and barriers to community integration. Tips offered by state advocates include:

### Mental Health-Focused Planning

- Broad-based disability coalitions are essential, but mental health groups also need to work closely in subgroups that meet regularly and develop detailed plans of their own.
- State plans should include a separate focus on mental health populations in state facilities to avoid losing track of their specific needs.
- The planning process should move expeditiously and involve mental health consumers, family members and other advocates.

### Facility- and Consumer-Focused Planning

The planning process should focus on specific state facilities and populations:

- How many people are in each facility and what are their specific treatment needs?

*see Olmstead on page 4-a*

## MHAs Respond to Proposed Restrictions In Services

Just one year ago, state coffers seemed to flow with funds for services for mental health, substance abuse, housing, employment and other vital needs. Today, many states are wrangling with budget deficits and considering substantial cuts to these systems. According to the National Governors Association, 29 states expect Medicaid spending to exceed their annual budgets.

This tight fiscal environment has provoked too many states to make budget cuts, and restrict access to needed mental health services and treatment. Understanding that such proposals jeopardize consumer health and can actually raise costs in the long run through increased use of more expensive interventions, MHAs are making a strong case for investment in mental health.

State legislative sessions are far from over, and it is clear that many states will be able to safeguard their current funds for mental health services or lower the level of spending cuts proposed. Some advocacy efforts have already demonstrated success in this restrictive environment.

### Florida Limits Medication Cuts

For the third year in a row, advocates in Florida have struggled against efforts to restrict access to medications in their Medicaid

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# An Interview With Steven Shon of the Texas Medication Algorithm Project

Many states across the country are carefully examining budgets and programs for psychotropic medications available through the Medicaid program. Although some states are mistakenly looking to apply closed formularies and other restrictions, the state of Texas has developed a system that guarantees consumer access to a choice of treatment options. The Texas Medication Algorithm Project (TMAP) offers practice guidelines for three major psychiatric disorders: depression, bipolar disorder and schizophrenia. Most important, TMAP is designed to ensure that consumers have access to a range of new, atypical medications and helps to avoid restrictions on access to mental health treatment.

Few clinical guidelines address the use of psychotropic medications, and patients sometimes report that their medication changes each time they change physicians. With the advent of new psychotropic medications, TMAP designers argue that physicians need a system through which they can integrate new information consistently. TMAP provides practice guidelines that operate like a flow chart of options that physicians and

consumers can follow. The first options include the newest and most effective medications. TMAP's philosophy is to decrease unnecessary variations in care while ensuring that patients receive optimal treatment that is tailored to their needs and symptoms.

Recently, NMHA staff met with Steven Shon, M.D., medical director for the Texas Department of Mental Health and Mental Retardation, to discuss TMAP and its implications for state policy.

**NMHA:** What is the research and conceptual foundation behind TMAP?

**Dr. Shon:** TMAP is derived from the concept of disease management, which takes a life-long disease and creates a program that effectively treats that disease throughout the life span of the individual. It encompasses three core elements of a disease management program: proper use of medications, patient/consumer and family education, and documentation across providers.

## Mental Health Is a Bipartisan Issue

In an NMHA analysis of mental health parity legislation being passed across the country, one thing is clear: Mental health is a bipartisan issue. Thirty-one states have enacted parity legislation, and the U.S. Congress is now poised to enact the Mental Health Equitable Treatment Act of 2001, which will help protect all Americans from insurance discrimination.

A growing number of legislators are recognizing that mental illnesses and mental health needs do not discriminate along party lines, and that mental health parity can improve access to real treatment. The chart below demonstrates how the passage of parity laws cuts across party lines.

At the national level, parity is being championed by legislators from both parties, including Pete Domenici, R-N.M., Marge Roukema, R-N.J., and Paul Wellstone, D-Minn. As the chart indicates, parity also enjoys tremendous bipartisan support at the state level.

### *Sponsors of state mental health parity legislation by political party*

	Full and Comprehensive Parity	Limited Parity	All Parity Laws
<b>Republican Sponsors</b>	13 percent	26 percent	22 percent
<b>Democratic Sponsors</b>	75 percent	74 percent	74 percent
<b>Republican Governors</b>	63 percent	52 percent	48 percent
<b>Democratic Governors</b>	38 percent	43 percent	48 percent
<b>Independent Governors</b>	—	4 percent	3 percent

For more information on mental health parity legislation, contact the Advocacy Resource Center at 800-969-NMHA (6642).

So, treatment is not focused just on an episode. It takes a life-long point of view and is based on the best science to treat an individual. This stands in contrast to the enormous variation that often exists in current practice. While it is important to provide treatments that vary according to individual symptoms, side effects and preferences, the same standard of care should be provided across the entire system. The algorithm helps guide physicians in terms of selecting medications, and, since all prescribers are using the same guidelines, it improves communication so that continuity of care exists and mistakes are not repeated.

**NMHA:** There have been some concerns raised by the mental health advocacy community that TMAP could be used by states to restrict access to treatment options. Is the TMAP program compatible with systems that restrict access to medications?

**Dr. Shon:** No. Access to the most effective medications is the first option available. TMAP supports open access to all medications that are effective for treatment of a specific disorder. Within an algorithm stage, TMAP does not favor one specific medication over another. Again, it is clinical judgment, and patient preference and acceptance that determine the choice.

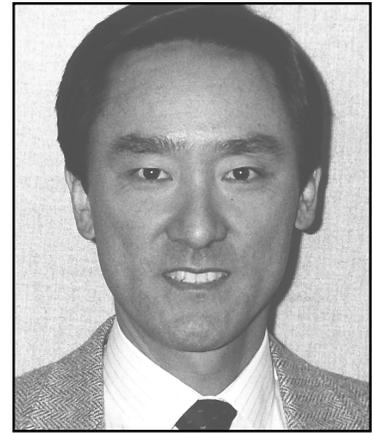
**NMHA:** When did TMAP begin and what have been the outcomes so far?

**Dr. Shon:** The program began conceptually in 1995 when we brought all stakeholders together and agreed that we should develop an evidence- and expert consensus-based algorithm to support treatment decisions. In 1997, we did a research study that measured outcomes and showed positive results in terms of level of symptoms and improved functioning. In 2000, we completed a large study with positive results that will be released later this year.

**NMHA:** Many states are looking at ways to control costs in the Medicaid program. Among states that are looking to replicate TMAP, have cost considerations been part of their interest?

**Dr. Shon:** Many states are looking to replicate the TMAP model, understanding that it may require some increased investment in the short run. New Mexico and Ohio have replicated the program and training has been

conducted in Washington, D.C., Florida, Georgia, Illinois and Virginia. Training is currently being planned for Kentucky, Louisiana, Nevada, Pennsylvania, Utah and Wyoming. TMAP will prove itself in the long run in terms of both improved health and economic savings through reduced hospitalizations and other interventions.



*Steven Shon, M.D., medical director, Texas Department of Mental Health and Mental Retardation*

But the positive outcomes associated with TMAP have led to increased investment rather than spending cuts. Advocacy organizations in Texas presented the data to the legislature and helped to get an additional \$27 million per year for new generation medications as well as \$8 million per year for community wrap-around treatment services.

**NMHA:** Beyond medications, what other services should a state have in place to make practice guidelines effective?

**Dr. Shon:** States need to analyze all of the parts of disease management, including housing, employment, psychosocial services and intensive case management, among others. Medication alone will often not get consumers to their highest level of functioning.

*Although NMHA does not endorse programs such as TMAP, questions from advocates across the country prompted this discussion with Dr. Shon. For information about key research on TMAP, visit <http://www.mhmr.state.tx.us/CentralOffice/MedicalDirector/tmap.html>. Practical information about TMAP can be found at <http://www.mhmr.state.tx.us/CentralOffice/MedicalDirector/tima.html>. In addition, NMHA has prepared a small packet of material for advocates who have requested information about TMAP replications being considered in their states. To request this packet, call the Advocacy Resource Center at 800-969-NMHA (6642). SAU*

*Olmstead* from page from page

- What funding streams are available for each consumer?
- What existing services are available and how can they be enhanced as people return to the community?
- People who are already in communities (or on waiting lists) should not lose their current services. Again, advocates must seek new resources to accommodate people already in living in the community and those returning from state facilities.

### High Level Buy-In and Funding

- Advocates should seek either legislation or an executive order to mandate that *Olmstead* planning be completed by a specific date with timely status reports to the legislature or governor.
- Few states are addressing the new resources needed to ensure effective *Olmstead* planning. The planning

process should include immediate efforts to expand the state's community-based capacity.

- Any savings from the closings of state hospitals and other institutions should be earmarked exclusively for the populations served.
- New financial resources should be sought from federal and state sources, and funding cuts should be vigorously opposed. States should take a full inventory of resources available at the local, state and federal levels, and target new funding to be sought in the legislature.

### Evaluation

- Evaluate and track time lines to ensure that they adhere to the *Olmstead* mandate requiring waiting lists to move at a reasonable pace. **SAU**

## CMHS Offers Incentive to Help States Promote Community-Based Care

The Center for Mental Health Services (CMHS) is offering grants to state Mental Health Authorities to help support their efforts to build and organize state coalitions that will promote community-based care for people with serious mental illnesses. CMHS will provide financial support to 50 states, plus the District of Columbia, Puerto Rico, and the Virgin Islands, of \$20,000 per year for a total of three years (subject to funding reauthorization).

This grant program complements CMHS's new National Coalition to Promote Community-Based Care, which is designed to promote the development of these state coalitions and provide technical assistance and training to state groups (see the January/February issue of *The Bell*).

CMHS created the coalition in response to the U.S. Supreme Court's decision in *Olmstead v. L.C. and E.W.*, which states that unnecessary segregation of people of people with disabilities in institutions is a form of discrimination that violates the Americans with Disabilities Act. The decision highlighted the need for states to provide community-based services that meet the needs of all individuals who can benefit from living in the community. The new grant program and coalitions will help focus the attention of states and other disability groups on the needs of people with mental illness.

MHAs and other advocates should be prepared for new coalitions in the states that have not begun *Olmstead* planning and for augmented efforts in states that have taken initial steps.

NMHA plays a lead role in supporting state advocates in their efforts to focus states on thorough *Olmstead* plans that include input from people with mental illnesses. Recent activities include a healthcare reform training with the Governor's Task Force and the MHA of South Carolina to develop a state plan and support coalition activities. In addition, NMHA recently convened MHA advocates from across the country to outline promising practices in *Olmstead* planning and other efforts to move people out of state institutions and into community-based services.

# Surgeon General Reports Are Essential Advocacy Resources

In the past two years, the U.S. Surgeon General's office has produced a number of landmark reports that offer key support to advocates working on a range of policy campaigns. All of these reports can be downloaded from the Surgeon General's Web site at <http://www.surgeongeneral.com>. A brief description of each follows:

## **“The Surgeon General's Call to Action To Prevent Suicide” (1999)**

This report introduces an initial blueprint for preventing suicide in the United States and addressing the associated toll of mental health and substance abuse disorders. Suicide is the third leading cause of death for young people between the ages of 15 and 24, and each year in the United States, nearly 500,000 people require emergency room treatment following attempted suicides. Leading experts developed 15 recommendations for the report that serve as a framework for immediate action to prevent suicide. Their recommendations are summarized below.

### ***Awareness, Intervention and Methodology***

***Awareness***—Develop public education campaigns to raise community awareness about suicide prevention and the resources available to at-risk populations. These campaigns should be designed to reduce the stigma and fear surrounding this issue.

***Intervention***—Provide training for healthcare professionals and family members on risk factors for suicide and how to access appropriate and quality treatment services. Implement primary care and school-based screenings for suicidal behavior.

***Methodology***—Support research efforts to identify evidence-based prevention programs that feature collaboration on the federal and state levels.

## **“Mental Health: A Report of the Surgeon General” (1999)**

This historic report states that mental illnesses are real, common and treatable, and that mental illness is the second leading cause of disability and premature mortality. Covered in previous editions of *The Bell*, the report provides an

extensive review of the scientific literature and of consultations with mental health consumers, family members and providers. It addresses important issues surrounding mental health including children with serious emotional disturbances, stigma and disparities in access to treatment services.

## **“Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda” (2001)**

The action agenda summarizes a series of activities that took place in the past year related to helping children with serious emotional disturbances, including the Surgeon General's Conference on Children's Mental Health held in September 2000. This report establishes goals and multiple action steps for improving children's mental health in the United States.

No primary mental health care system exists for children. Services and treatments are fragmented across many agencies and institutions—from schools to primary care settings to child welfare and juvenile justice systems. The report calls for greater coordination of mental health care services for families with mental health needs, and addresses disparities in access to care among racial and ethnic minorities and socioeconomic groups. These calls to action emphasize the importance of NMHA's goals, and its many programs dedicated to children and overcoming barriers to mental health treatment.

## **“Youth Violence: A Report of the Surgeon General” (2001)**

Three federal agencies collaborated with the Surgeon General on this report to develop strategies for addressing and preventing youth violence. The Centers for Disease Control and Prevention, the National Institutes of Health (which includes the National Institute of Mental Health) and the Substance Abuse and Mental Health Services Administration examined the factors that lead young people to commit violence and identified effective research-based prevention strategies. The report identifies 27 youth violence prevention programs that are evidence-based and have a proven record of success.

This report also challenged many of the false notions and myths surrounding youth violence that can lead to ineffective prevention strategies such as the beliefs that certain ethnic groups are more violent or that trying juveniles as adults reduces violent or criminal behavior. NMHA strongly supports recommendations outlined in the report to decrease gun use by youths, disseminate and implement model

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program. To rally opposition across the states, they have worked with stakeholders from several disease and disability groups. In the end, the state legislation limited access to medications, but mental health medications were among the classes of drugs exempted from restrictions. Although it is important to protect mental health consumers from limits on needed care, this is only a partial victory — mental health consumers have other physical healthcare needs and will also be harmed by any restrictions to access.

*To learn more about Florida's advocacy efforts, contact Juanita Hernandez Black at 407-843-1563.*

### **Indiana Wins Service Funding**

In Indiana, the state legislature has proposed substantial cuts in mental health spending and the creation of a closed Medicaid formulary. As in many states, Indiana's Medicaid program has experienced significant expense increases, particularly in the pharmaceutical line item of the budget. The Medicaid program has reacted by limiting access to needed medications.

The MHA of Indiana offered the legislature other ways to save money, such as disease management programs, and launched an advocacy campaign that included grassroots and direct lobbying, targeted media activities, and rallies at the state capitol. As a result of these efforts, Indiana advocates increased funding for community-based mental services by \$32 million in 2001. In addition, the legislature passed a bill prohibiting the Medicaid program from imposing formulary restrictions on psychotropic medications, although the governor has not yet signed the bill into law.

*To learn more about Indiana's advocacy efforts, contact Steve McCaffrey at 317-638-3501.*

### **Maryland Receives Mental Health Appropriation**

Mental health advocates in Maryland this year successfully garnered a \$30 million appropriation to address an estimated \$25-\$42 million deficit in the state's public mental health system. This one-time only funding increase is the largest of its kind in a single year for community mental health treatment in Maryland.

The state's mental health advocates are developing strategies to maintain and build on this level of support to ensure that those who remain underserved due to financial barriers can get the services they need. The MHA's approach examines public funding initiatives and the role of private insurers in covering mental health care for people who lack insurance.

*To learn more about Maryland's advocacy efforts, contact Linda Raines at 410-235-1178. SAU*

## **Healthcare Reform Advocacy Trainings** *Winter/Spring Calendar*

NMHA continues to provide advocacy trainings in conjunction with state and local affiliates geared to the specific needs and priorities of state mental health coalitions. Successful trainings conducted in 2001 so far include:

**Louisiana**—In February, the MHA of Louisiana brought together state advocates and NMHA staff to build support for Medicaid Buy-In legislation that would allow people on disability to maintain their Medicaid benefits after returning to work. Although the legislature did not pass the bill, the Department of Health and Hospitals has developed a plan to extend personal care services to all people with disabilities, which will serve a similar function as the Buy-In program.

**Oklahoma**—The MHA of Tulsa in March convened a statewide coalition to address managed care, community-based services and strategies to build systems of care for children. Following the MHA's advocacy efforts, the state's Department of Mental Health found in its budget an additional \$300,000 to help support a system-of-care pilot in Tulsa, and the state Department of Human Services has contributed an additional \$100,000. This pilot is expected to serve an added 30 children next year.

**Kansas**—In an effort to send a clear message to Washington, D.C., the MHA of Kansas met in March to develop strategies for passing parity legislation in the state. Following the training, the Kansas legislature passed a bill that was signed by the governor mandating that parity be offered in Kansas' health plans.

**Texas**—The MHA of Texas met in March to discuss efforts to expand its state's current parity law to include children with mental health needs. Thanks to advocacy supported by this training, the Texas House of

Representatives has passed legislation extending parity protections to children.

**South Carolina**—The MHA of South Carolina in March partnered with the Governor's Task Force on *Olmstead* to focus on the needs of people in state psychiatric facilities. The state director of the Department of Mental Health has committed to working with the MHA and other advocates as plans move forward to strengthen the state's system of community-based care.

**New York**—In April, the MHA in New York State met with its mental health coalition to discuss how to ensure open access to psychotropic medications in the state. It is too early to determine this training's impact, but it is clear that advocates made great strides in educating policymakers about the issue and reaching out to form partnerships with other disability groups, including those focused on AIDS and older Americans.

**Arizona**—In May, the MHA of Arizona will convene mental health stakeholders to build strategies to ensure access to mental health services and treatment for children in the state.

**Delaware**—Also in May, stakeholders will meet with the MHA in Delaware to better coordinate the state's mental health and substance abuse services.

If you anticipate problems regarding legislation or regulatory policy in the upcoming year or if you need to create or expand a mental health coalition, please feel free to contact us for assistance with your healthcare reform and advocacy efforts. We are ready to help.

For more information, contact Dave Nelson at 703-797-2594 or [dnelson@nmha.org](mailto:dnelson@nmha.org), or contact Erica deFur Malik at 703-837-3360 or [emalik@nmha.org](mailto:emalik@nmha.org).

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intervention programs, improve strategies for reporting crime and violent deaths, and to promote awareness of effective youth violence interventions.

#### **“National Strategy for Suicide Prevention: Goals and Objectives for Action” (2001)**

This is the second report from the Surgeon General on suicide prevention. This national strategy is designed to spark social change and to transform policies, services and public attitudes toward suicide. This report provides specific goals and action steps toward the development of services and programs to help prevent suicide and reach the suicide prevention goals outlined in Healthy People 2010 and “The Surgeon General's Call to Action to Prevent Suicide.” The objectives identified in this report promote changes that will affect the justice, education, social service and health care systems. The national strategy aims to:

- Prevent premature deaths due to suicide.
- Reduce the rates of suicidal behaviors.
- Reduce the traumatic after-effects associated with suicidal behavior, and the effect of suicide on families, friends and communities.
- Promote opportunities to enhance resources, respect and interconnectedness for individuals, families and communities.

A survey conducted for NMHA on the incidence of suicide in America underscores the importance of this issue and the need for immediate action to prevent suicide (see *Bell* cover story).

The Surgeon General also plans to release a report later this year on disparities in access to mental health services among racial and ethnic minorities. SAU

# Healthcare Reform Resources

NMHA is committed to providing mental health advocates and stakeholders with quality information that helps promote positive policy changes in states and communities. Below is a list of resources MHAs can use to help support their advocacy efforts. Most of these materials are available through the Internet. If you have problems accessing any of the following items, please call the Advocacy Resource Center at 800-969-NMHA (6642) and select option 6:

## Parity

From RAND—"Are People with Mental Illness Getting the Help They Need: New Findings About Parity Law, Insurance Coverage, and Access to Care," available at <http://www.rand.org/publications/RB/RB4533/>.

From the W. K. Kellogg Foundation—"Mental Health Parity: State by State," available by calling 800-819-9997 and requesting item #486.

## Managed Care

From the Kaiser Family Foundation—"The Characteristics and Roles of Medicaid-Dominated Managed Care Plans," available at <http://www.kff.org/content/2000/2180/>.

## Health Insurance Portability and Accountability Act of 1996

From the Department of Health and Human Service's Office of the Assistant for Planning and Evaluation—"The Administrative Simplification (AS) Provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA)," available at <http://aspe.os.dhhs.gov/admsimp/>.

## Children's Mental Health

From the Kaiser Family Foundation—"Access to Care for S-CHIP Children With Special Health Needs," available at <http://www.kff.org>.

From the Ambulatory Pediatric Association — "Annual Report on Access to and Utilization of Health Care for Children and Youth-2000," available at <http://ampe.allenpress.com>.

## Olmstead

From the Bazelon Center for Mental Health Law—"The Garrett Case: New Challenge to the ADA," available at <http://www.bazelon.org/garrettcase.html>.

From the Health Care Financing Administration—"Americans With Disabilities Act/Olmstead Decision," available at <http://www.hcfa.gov/medicaid/olmstead/olmshome.htm>.



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