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networks

Practical Information for State Mental Health Agency Professionals

ANSWERING THE CHALLENGE Responses to the President's New Freedom Commission Final Report

Speaking at the July 2003 NASMHPD Commissioners meeting, Michael Hogan, Ph.D., told the audience of state mental health officials that “There has never been a time when the interests of the states have been so closely aligned with the interests of the federal government.” An embodiment of this alignment in his roles as chair of the President’s New Freedom Commission on Mental Health, president of the NASMHPD Board of Directors, and director of the Ohio Department of Mental Health, Hogan was offering a preview of the content of the Commission’s final report, which was released later that month.

Almost a year later, the report, *Achieving the Promise: Transforming Mental Health Care in America*, continues to serve as direction for public mental health officials, topical fodder for advocates, and hope for consumers.

To revisit the report’s impact on the field of public mental health, *networks* has compiled a collection of viewpoints ranging from Commission members, to consumers who work in the field, to the federal officials charged with implementing the report’s vision into public mental health services nationwide. ◆

Federal Perspective: **Partnership with States is Essential**

By Robert Hennessy
networks Editor

The following article was compiled from phone interviews with Charles G. Curie, administrator of the Substance Abuse and Mental Health Services Administration (SAMHSA) and A. Kathryn Power, director of SAMHSA’s Center for Mental Health Services (CMHS).

Education, Justice, Administration for Children and Families, Veterans Affairs, CMS, the National Institutes, HRSA, and the Administration on Aging are brought together in a collaborative manner to develop a cross-systems mental health agenda for the first time,” he said. Curie added that the overall federal effort could be summed up in three parts: inventory, action agenda development, and action.

“Secretary Thompson [of the U.S. Department of Health and Human Services] tasked SAMHSA to serve as the lead agency to develop an action agenda from the Commission’s final report goals,” said Curie. “SAMHSA has several responsibilities, including ensuring that an inventory of current programs is taken at the federal level, and beginning a process of ensuring that federal agencies such as HUD, Labor,

As for the role of states, Curie said that the states will be primary partners in the transformation effort. “The states are where the action is when it comes to mental health,” said Curie. “I know from being a former commissioner [in Pennsylvania] that if there is to be a transformation across the country, it’s

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Report's Goals form Pillars for Transformation

According to the President's New Freedom Commission's final report, *Achieving the Promise: Transforming Mental Health Care in America*, the six goals listed below have been identified by the Commission as "the foundation for transforming mental health care in America."

The report's executive summary also declares, "The goals are intertwined. No single step can achieve the fundamental restructuring that is needed to transform the mental health care delivery system." For a free downloadable copy of the final report, visit www.mentalhealthcommission.gov

Goal 1:

Americans Understand that Mental Health is Essential to Overall Health.

Goal 2:

Mental Health Care is Consumer and Family Driven.

Goal 3:

Disparities in Mental Health Services Are Eliminated.

Goal 4:

Early Mental Health Screening, Assessment, and Referral to Services are Common Practice.

Goal 5:

Excellent Mental Health Care is Delivered and Research is Accelerated.

Goal 6:

Technology is Used to Access Mental Health Care and Information. ♦

Campaign Created to Help Pursue Commission Goals

Compiled from staff reports and www.mhreform.org

The Campaign for Mental Health Reform is a collaboration of advocacy organizations formed to become the mental health community's united voice on federal policy.

The Campaign's goal is to make access, recovery, coherence, and quality in mental health services the hallmarks of the nation's mental health system. It works directly with federal policymakers to make this a reality.

The founding partners are the National Association of State Mental Health Program Directors (NASMHPD), the National Mental Health Association (NMHA), NAMI, and the Judge David A. Bazelon Center for Mental Health Law.

Other partners include:

- ◆ American Psychiatric Association
- ◆ American Psychological Association
- ◆ CHADD - Children and Adults with Attention-Deficit/Hyperactivity Disorder
- ◆ Consumer Organizing and Networking Technical Assistance Center (CONTAC)
- ◆ Depression and Bipolar Support Alliance (DBSA)
- ◆ Federation of Families for Children's Mental Health (FFCMH)
- ◆ International Association of Psychosocial Rehabilitation Services (IAPRS)
- ◆ National Association of County Behavioral Health Directors (NACBHD)
- ◆ National Council for Community Behavioral Healthcare (NCCBH)
- ◆ National Empowerment Center (NEC)
- ◆ National Mental Health Consumers' Self-Help Clearinghouse
- ◆ Suicide Prevention Action Network USA (SPANUSA)

William Emmet is the coordinator of the Campaign for Mental Health Reform. For more information, or to contact Mr. Emmet, visit www.mhreform.org ♦

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Consumer Panel Responds to Commission Report

In the spirit of transformation to a consumer-driven mental health system, *networks* interviewed four consumer/survivors who work in the field of public mental health to obtain stakeholder feedback on the President's New Freedom Commission's *Achieving the Promise: Transforming Mental Health Care in America* report. The panel participants include Karen A. Kangas, Ed.D., director of Community

Education and Recovery Affairs, Connecticut Department of Mental Health and Addiction Services; Thomas Lane, director of the NAMI Office of Consumer Affairs; Jacki McKinney, founder of the National People of Color Consumer/Survivor Network; and Dan Powers, J.D., past president of the National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA).

There wasn't much to "go about" since I didn't have a job and my kids weren't with me. I think now that we are involved, there is a lot of hope given to consumers. We are talking about recovery, and once you start talking about it, it becomes an expectation that you can recover. This changes not only those of us who have mental illness, but also those who provide the services. Another part of the goal is the right to be respected and treated with dignity. We are not treated with equality. This is clear when you go to the appointment, and also with housing, and even access to care. Goal 1 [Americans Understand that Mental Health is Essential to Overall Health] is also encouraging in terms of its discussion of discrimination. With this on the national agenda, we could really look at preventing suicide. The numbers of deaths are way too high because people don't seek treatment. They are afraid to sit in mental health offices, and they don't go and get help.

1 In your opinion, how will the report benefit consumers?

Kangas: The report really puts mental illness on the national agenda. The fact that everyone is learning about it and hearing about the President discussing it will hopefully make things better.

Lane: There are a couple of ways – obviously the six goals provide opportunities for consumer/survivors to move forward in implementing those goals. Some of the goals are more inline with the types of things that the consumer/survivor movement and the individuals in the movement are more able to do, more equipped to do, but I think it will provide a focus for some partnering. It's like [Commission Chair] Mike Hogan said, it's more of a catalytic report than a determinate report. Hopefully it will spur a critical mass for moving forward as a coalition of consumer/survivor organizations toward implementing these goals.

McKinney: In the past, important documents like this have been able, for at least a short period of time, to raise the awareness of consumers and family members that somebody is looking at mental health from a very high level. The fact that this report has the backing of the President has gotten it more media, so, more people have had more access to the ideas in it. Unfortunately, I don't think it has reached the public that I'm concerned with—poor people, people of color, and consumers. I don't think the

people at the bottom of the pecking order really know a lot about it. Those of us who are consumers and have a connection with federal, state, or local government are aware because I think all of those [government] entities are on board. However, I think there is some level of awareness that the report is out, and that is a good thing for consumers.

Powers: It's a very comprehensive report. It addresses a whole gamut of issues and that is its strength. Particularly, it mentions housing, reducing seclusion and restraint, and serving the incarcerated. These are areas that are very important to consumers and they need to be addressed.

2 What do you feel is the most important goal of the six report goals to accomplish for the field of public mental health?

Kangas: Because I am a person with mental illness, and have been in a state of recovery—a lonely process because mental illness is not talked about—I think that the most important goal is Goal 2 [Mental Health Care is Consumer and Family Driven]. I don't think that it has been consumer driven. Recovery has not been a part of our plan of care. Many of us would like to lead a plan a care. If it is not our plan, we are not going to follow it. I think that's an important part of this goal. For so many years, I had no hope. My psychiatrist said I would never work again. He told me to go about your life.

Lane: I think they are all important, though I would say that Goal 2 is the most important. Why? Because that goal is the one that allows the most sweeping opportunities for participation. Some of the recommendations that came from the Center for Mental Health Services consumer/survivor advisory subcommittee were consistent with some of the other Commission goals and recommendations (such as instituting a national database of consumer services), but I think that Goal 2 speaks to the essence of what the transformation could look like if in fact we could accomplish this goal and have mental health care be consumer and family driven. If the outcomes were determined by the people using the services, that would be great. Mental health care needs to be more market driven.

McKinney: For me, this question goes back to being a consumer and a person of color—both are rife with stigma. Without talking about stigma, racism, discrimination, this conversation doesn't sit well with me. I can't divide those two

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Consumer Panel

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issues. So, I would say that the most important goal would be Goal 3 [Disparities in Mental Health Services Are Eliminated]. I believe that if we eliminated stigma, some of the disparity would disappear. I think stigma stops me as a consumer, and its first cousin racism are together what stop me from seeking supports because my community is so sensitive to stigma. They don't talk about mental health. So, eliminating the disparities is very important. There is somewhat of a divide between the larger community and consumers, but eliminating stigma would lesson this.

Powers: To me the most important goal is Goal 2. In this goal, the commission members talk about some of the issues that are very important to consumers. One thing that I think is very important is the number of persons that are incarcerated and have a mental illness—this is a very serious challenge for the states. They also talk about making housing supports a priority. This is another big issue for consumers. The reduction of seclusion and restraint is also addressed under that goal. For all these reasons, Goal 2 is most important.

3 What can consumers do to help accomplish some of the goals in the report?

Kangas: Its' a continuation of things we have been doing. I have been doing it for 15 years, and we advocates need to continue to be out in front. However, we need more help with this, and I am always concerned about people in the private sector, and those who have insurance, and those who have jobs they don't want to lose, and they are afraid and ashamed to say they have mental illness. They will not go public, and as long as we can't go public, it will continue to be a secret and we will not get better. We need to encourage more people to talk about their mental illness. We need to be good examples of people in recovery, spend some time with the media, having Public Service Announcements on TV with

people in recovery, putting us in a more positive light.

Lane: A lot of people are already doing things to accomplish the goals. The CMHS Consumer/Survivor Advisory Subcommittee has looked at the Final Report and come up with some recommendations specifically under Goal 6 [Technology is Used to Access Mental Health Care and Information] that they passed on to the SAMHSA National Advisory Committee. I was at the NAC/SMHA meeting and I am aware that NAC/SMHA as a body is also making some recommendations to NASMHPD in reference to the New Freedom Commission report. So I think there is work in progress and people are looking at this as a focal point of activity. In keeping with this direction, NAMI's National Consumer Council hosted a forum in November in Baltimore. The

“You can't write stigma away, you have to educate stigma away, and consumers can help the larger community learn more about mental illness.”

event was a roundtable discussion on a partnership platform for change. The framework was the President's Commission goals. The NAMI National Consumer Council hosted this discussion to develop an action plan toward accomplishing the goals and following some of the recommendations. This is some tangible work—the nuts and bolts, rubber to the road type of activities and cooperation that needs to happen to accomplish the Commission's goals.

McKinney: Consumers can put a few words on their chest, on their mantle piece, or on some place of visibility. One phrase would be “Culture counts,” and another is “Stigma has to stop.” You can't stop disparity without dealing with stigma. It isn't going to happen. You can't write stigma away, you have to educate stigma away, and consumers can help the larger

community learn more about mental illness.

Powers: I think when you look at the report, you realize that a lot of the things have to be done by public officials. I think consumers need to be informed about what's in the report and then must advocate with their senators, congressmen, and state legislators to implement and accomplish the goals. Consumers being organized and bringing pressure to bear to accomplish these goals is an important step in this process.

4 What can NASMHPD do to help involve consumers in the process of achieving these goals?

Kangas: NASMHPD has done some really excellent things in reference to reducing seclusion and restraint, but I don't think we consumers are involved enough. NASMHPD has collaborations with NAMI and NMHA, though no real consumer groups. Although we are in all those groups, it would be nice to have a real consumer-organized group to be a part of the Campaign for Mental Health Reform. And also, people on the groups should be able to disclose their own status in reference to recovery. I think there should be some NASMHPD Meet-Me Calls where commissioners and people in recovery could be on the same call so there is better dialogue.

Lane: I think that NASMHPD has a great resource in NAC/SMHA. I appreciate Dr. Glover's commitment to support NAC/SMHA, and I would love to see this continue. To rely on NAC/SMHA to be its liaison to the consumer movement, to get the grass roots perspective on what is really going on in the movement. NAC/SMHA is a great knowledge base. So are organizations like NAMI and NMHA and other advocacy and activist organizations.

McKinney: NASMHPD can ask the state mental health directors and their constituents to set aside a day to support discussing mental illness. Then they should develop a toolkit on discussing

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Transforming Mental Health Care for Children and Families

By Larke Nahme Huang, Ph.D.

The President's New Freedom Commission on Mental Health, in its final report, *Achieving the Promise: Transforming Mental Health Care in America*, outlines 19 policy recommendations that will reconfigure resources, services, and supports to better meet the mental health needs of children and adults with mental disorders. This report is the result of a year-long intensive study of the existing mental health care delivery system and the finding that, while well-meaning individuals staff the system, the system itself is "fragmented, disconnected and often inadequate, frustrating the opportunity for recovery."

The Commission arrived at the resounding conclusion that large-scale systemic transformation is necessary in order to achieve the promise of enabling adults with mental illness and children with serious emotional disturbance to live, work, learn and fully thrive in their homes and communities. This article will highlight selected findings on the state of mental health for children and youth, address implications of the Commission's policy recommendations for children and families, and preview the Commission's Subcommittee report on Children and Families.

Our nation faces a public health crisis in the mental health status of children and youth. Recent estimates show approximately one in five children with a diagnosable mental disorder and one in ten with a severe emotional or behavioral disorder causing significant impaired functioning at home, at school, or in the community (Commission on Children at Risk, 2003; Friedman, Katz-Leavy,

Manderscheid, & Sondheimer, 1996; Leaf et al., 1996). These disorders are frequently complex, involving multiple problems and diagnoses, and multiple child-serving systems. For a substantial portion of these children, their disorders may be long-lasting and can persist into adolescence and adulthood.

Co-occurring mental health and substance abuse disorders are increasingly prevalent with recent studies indicating that of youth treated for substance abuse disorders, 80% to 85% also have a mental health disorder (Greenbaum, 2000). In the National Comorbidity Study, Kessler et al (1994)

Despite an increased awareness of mental health problems, children remain an underserved population with up to 80% of children with emotional and behavioral disorders not receiving mental health services.

report that the median age of onset for mental health disorders was 11 years old with the median age of onset for substance abuse five-to-ten years later.

There is an increasing incidence of mental health problems among young children; in 1997, 120,000 low-income preschoolers were in mental health care and between 1991 and 1995, there was a 300% increase in psychotropic medications for 2-4 year olds (Rintoul, 2003). Forty-four percent of children in

foster care are infants and toddlers and, increasingly, young children are being expelled from childcare or early education programs due to emotional and behavioral problems. For youth in other child-serving systems, there is a similarly alarming level of mental health problems. In the juvenile justice system, rates of mental health disorders range from 52% to 66% (Teplin et al., 2002). Of the approximately 500,000 children in foster care, it is estimated that up to 85% of children have an emotional/behavioral and/or substance abuse disorder.

Despite an increased awareness of mental health problems, children remain an underserved population with estimates that up to 80% of children with emotional and behavioral disorders do not receive mental health services (Ringel & Sturm, 2001). The problem of unmet need is particularly severe for children from racially and ethnically diverse backgrounds (U.S. DHHS, 2001). For example, African American and Latino children are identified and referred at the same rates as the general population but are much less likely to receive specialty mental health services or medications (Kelleher, 2000) and children of color are more likely to receive mental health services through juvenile justice and child welfare systems than through schools or mental health settings (Alegria, 2000).

So, what is the "promise" for these children and their families? What is in the Commission report that will be "transformative" for these children? Is there a recommendation that is considered "the child recommendation"? In the final report, there is *not* a "designated" child-specific recommendation. No single recommendation will transform mental health care and outcomes for children. Rather, specific policy recommendations and implications for children and families are incorporated in each one of the six goal areas. It is in the aggregate that these

Dr. Huang served as a Commissioner on the President's New Freedom Commission on Mental Health and co-chaired the Subcommittee on Children and Families. She is a senior policy associate at the National Technical Assistance Center for Children's Mental Health and the director of research in the Center for Child and Human Policy at Georgetown University.

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Children & Families

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recommendations will begin the transformation of mental health care for children. Some of these recommendations, embedded in various goal areas, are described below.

Family-Driven Care (from Goal 2) challenges the current system in which families have little influence over the care their children receive. Families of children with serious emotional disorders experience a high burden of care and wide-ranging impact of these disorders on their quality of life and productivity (Shonkoff & Phillips, 2000). Yet, families also indicate that they are a “silent army,” ready to partner in the care of their children and provide guidance in the planning of services at the program and system level.

The Commission promotes a family-driven system in which the family’s needs and preferences drive the policy and financing decisions that affect them. Care is consumer and family-centered with families working in full partnership with providers. Key federal child-serving agencies (e.g., SAMHSA, Education, Administration for Children and Families, and Office of Juvenile Justice and Delinquency Prevention) should work across systems to clarify and coordinate regulations and funding guidelines and design policies that support families as respected partners in service delivery and system development.

Additionally, as continuous, 24/7 providers for their children, families can often be overwhelmed by the demands of care-giving without family-oriented services and supports. Respite services provide temporary relief for caregivers yet financing these services has been difficult. The Commission proposes a Centers for Medicare and Medicaid Services (CMS) demonstration that would expand the ability of states to develop respite care service alternatives beyond the scope of a home and community-based waiver and test the financial impact of this service.

Family Access to Information and Support (from Goal 6) is integral to a family-driven care system. Most families

want relevant and cutting-edge information about mental disorders, symptoms, treatments, and supportive services relevant to their child’s disorder. However, this information is difficult to access in a timely manner. The Commission proposes technology information and support that enables families 1) to readily access information regarding best practice models, scientific research, relevant health information, and available services and supports, and 2) to maintain a personal electronic health record that integrates behavioral health data from multiple systems and sources to support decision-making regarding the child’s care.

This coordination of data and enhanced communication between

For children who need multiple services and supports, the burden of coordination and access to care should be shared by families and service providers.

informed family members and behavioral health care providers contributes to more knowledgeable decisions and treatment planning and mitigates against fragmentation in services for children.

An Individualized Single Plan of Care (from Goal 2) helps overcome the problems that result from fragmented, uncoordinated services and systems. Children with complex mental disorders often cross multiple systems, each with its own plan of intervention. A child in this situation may have an individualized education program (IEP) in the school system, a family preservation plan in child welfare, and a treatment plan in the specialty mental health sector. Rarely are these plans coordinated across systems; rarely is there a single case coordinator.

An individualized single plan of care forms the basis for care that is family-driven, customized to the needs of the child, appropriate to the culture and language of the family, constructed in full

partnership with providers, and coordinated across different programs and agencies. For children who need multiple services and supports, the burden of coordination and access to care should be shared by families and service providers. In contrast to currently siloed funding streams, the funding for this customized plan follows the child.

The Commission recommends legislation to implement the CMS demonstration proposed in the FY 2004 budget, “Money Follows the Individual” Rebalancing. This demonstration creates flexible financing for long-term services and supports that enables funds to move with the child to the most appropriate and preferred setting as the child’s needs change. To the child and family, the movement of funds is seamless, and is linked to the State’s adjustment of Medicaid programs and services to achieve a more equitable balance between the proportion of funds used for institutional services and community-based services and supports. The Commission recommends technical assistance to families in developing individualized plans of care and networking with other families.

A Broader Array of Services and Supports (from Goal 2) for children and families is critical to enabling children with serious emotional disorders to remain in their homes and communities. It is also critical to eliminate the need to “trade custody for mental health care,” a practice which results in parents relinquishing custody of their child in order to obtain mental health services through the child welfare or juvenile justice systems. A broader concept of mental health services, beyond the traditional inpatient, outpatient and long-term residential care, should be developed and financed. This would include a comprehensive array of services and supports (e.g., behavioral aides, mentors, medications, etc.) that enable youth to reach and maintain their optimal level of functioning in their homes, schools, and communities.

The Commission recommends

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Q&A with Michael F. Hogan, Ph.D.

1 Recommendation 2.4 of the report's second goal (Mental Health Care is Consumer and Family Driven) is to create a comprehensive state mental health plan. What/who are the most appropriate entities to accomplish this?

The context for this recommendation is the commission's discovery that, these days, most of the problems with mental health care are outside of the specialty mental health system, and are in agencies or programs such as prisons, welfare, juvenile justice, etc., over which State Mental Health Agencies (SMHAs) have very limited control. With this scenario as the backdrop, the commission's idea was to elevate leadership for a plan for mental health care within the states to a level where the government would pay attention to, and perhaps direct the overall approach, and where the SMHA would be empowered to provide leadership and collaborate in a more aggressive way with other entities to develop a more comprehensive plan.

2 What do you see as NASMHPD's role in helping to create such plans?

NASMHD has three roles. First, NASMHPD should advocate with SAMHSA for a framework for this planning that will be responsive. The second role would be to provide support, guidance and leadership to member states on how to approach the task. The third role for NASMHPD, as we get more experience on this, is to advocate with other federal entities—such as Medicaid,

vocational rehabilitation, special education, and corrections—that are major funders of mental health care in sectors outside the specialty mental health system.

3 Can these plans be created and implemented without new resources/funding?

I think the question of whether newer resources are needed depends on the adequacy of the resources now in any given state. There are clearly places where expenditures on mental health care have skyrocketed outside the mental health system. We know that the hidden costs of homelessness are greater than the cost of supported housing. We know that mental health is a significant multiplier of medical costs for people with other illnesses—especially chronic illnesses—in Medicaid. As one example in Ohio, we found that the Memphis, TN-based [Police] Crisis Intervention Team model, a collaboration between mental health and police, requires an initial investment on training, though it frees up a huge amount of cost to police. So, there

are going to be big resource questions, but it's not clear what kind they are yet.

4 As a state mental health commissioner and as the former chair of the President's New Freedom Commission on Mental Health, do you have specific advice for this proposed effort?

To people working in the State Mental Health Agencies, start thinking about this effort now. Inventory the collaborations that can be built upon. Consider how a healthier mental health department in your state can contribute to your governor's priorities. Think about the framework of this planning that will emerge from SAMHSA and CMHS. Begin preparing shareholders, certainly including the planning councils, for these expanded possibilities. As far as working with other states, review whom you network with, who you have similar structures with. If you can develop a relationship with a state that's got a similar situation, it's tremendously valuable. ♦

“Consider how a healthier mental health department in your state can contribute to your governor's priorities.”

Drop us a line...

If you have ideas for a future issue of *networks*, or if you would like to be a contributing writer for *networks*, contact Robert Hennessy, editor.

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Dr. Hogan served as chair of the President's New Freedom Commission on Mental Health, and is the president of the NASMHPD Board of Directors, and director of the Ohio Department of Mental Health.

Legislative Efforts are Aiding System Transformation in Nevada and South Carolina

By Robert Hennessy
networks Editor

According to many public mental health officials familiar with the President's New Freedom Commission on Mental Health, the legacy of the Commission's final report is yet to be formed. "What we do with it is more important than what's between the covers," is an oft-heard expression in the advocacy community in particular, referring to what many feel is a timely opportunity to transform the nation's behavioral health system into a consumer-driven, recovery-focused system.

The challenge to state mental health agencies is to harness the opportunistic environment created by the final report and utilize it to jump start system transformation. The Nevada and South Carolina State Mental Health Agencies (SMHAs) are two of several state-level agencies working with their legislators to make system transformation an official government priority.

According to Carlos Brandenburg, Ph.D., administrator of Nevada's Division of Mental Health and Developmental Disabilities, the Nevada Mental Health Plan Implementation Commission was formed to guide the transformation effort in the Sagebrush State. The Nevada Commission is tasked by Nevada State Senate Bill 301 to "Determine how Nevada will implement the recommendations of the [final report] ... to enable adults with serious mental illness and children with serious emotional

disturbances to live, work, learn and participate fully in their communities." Under this same law, the commission is tasked to develop an action plan for the implementation, and then outline and deliver the plan to the governor's office by January 1, 2005.

"We have to give the [President's Commission final report] some legs," said Brandenburg. "The only way we can do this is to empower the SMHAs to implement the plan." Brandenburg credits legislative champions such as Nevada state Sen. Randolph J. Townsend, M.Ed. with turning the President's Commission vision into state-level practice.

Townsend, the only elected official on the President's Commission, contacted Brandenburg with the idea of writing the Nevada implementation law.

"We have to give the [President's Commission Final Report] some legs. The only way we can do this is to empower the SMHAs to implement the plan."

Months later, the Nevada Commission is making progress. The group has had four meetings (as of this writing), with a goal to have at least one meeting for each major goal of the President's Commission final report.

A notable feature of the Nevada Implementation Commission is its membership: three members each from the state senate and assembly (including Townsend); the SMHA administrator

(Brandenburg); the substance abuse administrator; and the chief officer of both the Division of Health Care Financing and the Division of Child and Family Services.

Brandenburg lauds the group's composition. "This has truly been a bi-partisan effort. Liberal Democrat and conservative Republican have combined to be the strongest advocates," he said. "The diverse makeup will enable us to look at the President's Commission recommendations and decide what our state's task is going to be."

Both Brandenburg and Townsend believe that stakeholder input is key to a successful implementation strategy for states. During his tenure on the President's commission, Townsend would host a town forum on each upcoming issue that the commission was prepared to discuss at its next meeting (homelessness, children's issues, etc.).

The meetings involved consumers, family members, clinicians, and stakeholders from all parts of society—inside and outside of the mental health field. These forums informed the senator with invaluable feedback for his participation in the President's Commission, and the Nevada Commission has modeled its meeting structure in the same representative fashion.

Involving stakeholders, according to Brandenburg, is essential for illustrating why system transformation is necessary. "You need consumers and family members and people from the business community to spell out why transformation is needed," he

said. “You need business people to say why treating mental illness more appropriately and getting people off entitlement is good for business. You need to have the sheriff talk about taking people with mental illness out of the county jails. You need to have people in public health talk about incorporating mental health services into the front end instead of the back end. And, you need to have stakeholders do this in unison for best effect,” said Brandenburg.

In early November, Brandenburg was among a distinguished group of advocates who testified before the United States Senate Subcommittee on Substance Abuse and Mental Health Services of the Health, Education, Labor and Pensions Committee, which was holding its first hearing on the President’s New Freedom Commission on Mental Health.

In his remarks, Brandenburg said, “Ultimately our [state] commission will show Nevada how to change the fragmented nature of our mental health delivery system... For example, enhanced education about mental illness would greatly improve the general public perception of mental illness and also increase the understanding that mental illness impacts overall health, and that mental illness is treatable and recovery is possible.”

SOUTH CAROLINA EFFORTS

Amid the deceptively lazy sway of the palms in the warm breezes of the Palmetto State, South Carolina’s Department of Mental Health is also involved in an aggressive effort to make system transformation a legislative priority. The effort is intended to operationalize the final report’s goals and recommendations into the SMHA’s structure, doctrine, and practice.

According to George Gintoli, director of South Carolina’s Department of Mental Health (DMH), the agency is working with its state legislators to draft legislation that would enable the department to adopt the goals of the final report as the department’s goals. Gintoli says that the effort is intended to bring about system transformation in South Carolina that is specifically aligned with the President’s Commission’s efforts.

The South Carolina effort will include a kickoff event, the creation of work

“This effort will set a long-term legislative mandate—no matter who the director is—to declare that working toward these goals is necessary for the system.”

groups to focus on each final report goal, and a steering committee to see that the work carries on through administrative turnover, even at the SMHA commissioner level. “My agenda is to sustain some continuity of care so that a new state director would not change the platform,” said Gintoli. “Essentially this effort will set a long-term legislative mandate—no matter who the director is—to declare that working toward these goals is necessary for the system.”

Not only is the South Carolina DMH helping draft the legislation, they are also proactively working with other state-level agencies such as the department of drug and alcohol abuse, the department of health, the state Medicaid agency, vocational rehabilitation, corrections and juvenile justice to gather input and support for the initiative.

The initiative began during the DMH’s recent strategic planning process, when officials decided that to give weight to any system transformation

effort, the department would need to seek legislative support.

However, while the potential legislation is important to the process of transformation, Gintoli says that the power of the effort is in the people. “For other states looking toward legislation to aid in their transformation effort, I would start with the grassroots organizations—the consumer groups, the local NAMI offices, the local NMHA offices—to make sure they are on board and at the decision making table,” he said. “Then bring on some champions in the legislature, and start working with them to let them know what this [transformation effort] is all about. Educate them, and be sure to let them be a part of the ownership of the transformation, rather than coming in too late in the game.”

Gintoli believes that the sky is the limit to the SMHA’s effort to operationalize the goals of the final report. “I’m hoping that as a result of this enabling legislation and stakeholder input that we can truly focus on transformation. We could have a stronger community-based system, a more integrated system with other pertinent state agencies, promotion of the integration of primary care and mental health, and an improvement of rural access and care. I also think this effort will have a positive impact on the reduction of stigma,” Gintoli said.

Nevada and South Carolina are just two of the states who are utilizing legislative tools to empower the transformation effort envisioned in the President’s Commission final report. For more information on these efforts, feel free to contact the Nevada Division of Mental Health and Developmental Disabilities, the South Carolina Department of Mental Health, or NASMHPD. ◆

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critical that states are in a lead position to make sure that it happens, and that is gets translated at the local levels as well.”

A. Kathryn Power, Curie’s internal agency lead for the transformation effort, also is looking to the states to answer the challenge of the Commission report. “States are *crucial* partners with CMHS – we can do nothing without the states,” she said. “As a former president of NASMHPD, and a former commissioner in Rhode Island, I have a very keen respect for the states. I believe the states are the focus of change, and I also trust that the states will have relationships with local authorities that we will need in order to make the kind of transformation that is envisioned in the report.”

SAMHSA’s first step on the post-report road to transformation was to conduct an inventory of existing Department of Health and Human Services (HHS) programs, services, and contracts to review which efforts currently reflect or inform activities of all six goals of the Commission final report. According to Power, the SAMHSA inventory was recently completed, and CMHS is working with other federal agencies to perform their own inventories.

“The second step is that other HHS agencies and some outside of HHS are currently doing that inventory and will report back,” she said. “We are also asking CMHS staff to tell me what they could do, or may have been planning to do, or may want to do, that supports each of the six goals.”

The third step according to Power is to “Define what we mean by transformation,” she said. “I see *Achieving the Promise: Transforming the Mental Health System of Care* as my job description. So if that’s my job, I want to know not only what the President’s Commission members envisioned for transformation, but also what the individuals at the local, state and national levels think, as they will be the ones engaged in the transformation effort.” To

define the effort, CMHS has been engaged in grass roots research including informal discussion groups with constituents.

“When we achieve all six goals, we will be moving toward a transformed system of care,” said Power. “But the act of transformation is really a constant iterative focus on change. Transformation is a process, an output, an attitude, and that is a very important discussion to be had as we set about activities focused on transforming the system,” she said.

As for tangible assistance, SAMHSA is recommending that states begin—if they haven’t already—their own

SAMHSA recommends that states conduct inventories to determine how they will approach the transformation effort, and which tools and resources they will need from SAMHSA to accomplish the goals.

inventories to determine how they will approach the transformation effort, and which tools and resources they will need from SAMHSA to accomplish the goals within their states. State feedback is essential to future federal budgeting efforts, particularly for the '04 and '05 budget years, according to Power. “We need to know more about what kind of support is needed, what kind of technical assistance, what kinds of grants, policy academies, and focus programs are most useful,” she said.

“Since each state is going to look at transformation a little bit differently, they may have a different level of need,” Power added. “So, we need to know where each state’s infrastructure is. How do we provide supports for states that will help them embed recovery into their systems? What can we provide them by way of research and continuing model programs and pilot programs? We are going to look at all of the mechanisms that we have available to support the transformation,

and I think that we’ll have a sense of that progress in '04,” she said.

While it’s premature to discuss '05 funds at this point, according to Curie, he discussed the possibility of resources for states in the future. “It’s anticipated that as far as the action agenda is concerned, i.e. those types of activities that a state needs to be doing in order to pull together a real state mental health plan for example, SAMHSA is committed to examining its current resources for possible redistribution, and looking for appropriate ways to ask for new resources to help states with that process,” he said. “We recognize that when you are looking at an up-front planning process, it’s certainly helpful to have up-front resources to jump start activities,” said Curie.

Structural changes are probably not in the mix for SAMHSA/CMHS, according to Curie, but there may be some reorganization of federally funded programs. “We went through a restructuring process at SAMHSA when I first came aboard, and I think in terms of our structure that we are pretty well set as we have been keeping in mind all along the fact that we would be responsible for mental health transformation as a result of the commission report, so there are no restructuring plans right now,” said Curie. “However, I will point you to the [SAMHSA Programs & Principles] Matrix, which will be our ongoing way of managing and aligning resources to assure that the priorities are being addressed sequentially and chronologically on an action agenda for attaining the report’s goals. As we look at funding for the next several years, we will be doing this by ‘Matrix Management’ – assuring that the right people are pulling together on the right priority,” he said.

Power added that, “If there are some programs which we feel are not consistent with supporting transformation, we may shift them. We will redirect some of our resources that we believe should be more focused particularly on the six goals and the 19

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Q&A with Stephen W. Mayberg, Ph.D.

1 In your opinion, what is the core message(s) of the Commission's final report?

The first core message is that in spending a year analyzing the mental health system in the United States, we realized that you need a substantial change to make the system more responsive. That's why we call it "transformation" of the system. What that comes from is a reliance on, and the belief in, recovery and resilience. Second, it's important to understand that we don't always use those things that work (i.e. we know that recovery is possible, but we don't always make use of the knowledge we have). Third, we need to realize that our system is so fragmented and disconnected that it's very difficult for anyone to negotiate the system.

2 What is the biggest accomplishment of the commission process overall?

We were able to listen to so many people and engage so many different constituencies, and many of the constituencies have made the commitment to move forward with implementing some of the recommendations. A classic example is the Campaign for Mental Health Reform, with the National Mental Health Association, NAMI, Bazelon, and NASMHPD working together as primary partners to actively pursue making sure this happens. The Commission process was just as important as the content. The

Dr. Mayberg served as a member of the President's New Freedom Commission on Mental Health, and is president of the NASMHPD Research Institute, Inc. Board of Directors, and director of the California Department of Mental Health.

fact that this effort has the imprimatur of the President gives the effort credence in lots of different arenas.

3 Which goal, or which recommendation within a goal, has the most immediate potential/possibility for states to fulfill, and why?

The most complex goal—but one that needs to get started—is Goal 2 (Mental Health Care is Consumer and Family Driven), especially the issues of individualized treatment planning (or care planning) and an integrated state plan, and these recommendations are connected. The most quickly attainable activities for states will be looking at some of the Medicaid financing options, or taking advantage of some of the waiver opportunities or technical assistance, or being able to use some of the information

technology from Goal 6 to forward their agenda.

4 Where do states fit in to the picture?

The states were very well represented. There was very good recognition of the importance of the states in the effort to transform the system. There was a hope that rather than this report being prescriptive to them, states could take the initiative to start making changes. It reflects some of the new federalism that there was no concrete mandate, but an implied challenge from the Commission: *You are a major player; do what you can to move the system forward.* I have every faith that the mental health commissioners, the states, can and will do that. The fact that we are writing about this is a sign that NTAC/NASMHPD is doing what it can to keep this agenda alive. ♦

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mental illness that any consumer could pick up and take to a school meeting and present it. A very simple toolkit; not one that is so sophisticated that you have to bring your thesaurus and laptop to look up half the words. The toolkit should be one that a mother could take to her children's school to tell the staff about how her child is different, and how the child may need special care. This type of toolkit would be great for families and consumers to be able to take and use at school fairs, neighborhood events, etc. The educational material has to be easy to read and use for everyone. This can help consumers bring their issue to the table. Many people in my community don't watch television, so the dialogue is what's important—to have people talking about mental illness.

Powers: I think they can work with their offices of consumer affairs. Most states can help consumers achieve the goals. I would like to see NASMHPD do something that focuses more on persons in the criminal justice system who have mental illness. State commissioners can work with criminal justice folks to devise more ways to keep people with mental illness out of the criminal justice system.

5 Do you have specific advice to states as they work toward achieving the goals of the report?

Kangas: In Connecticut, we are trying to look at collaboration. In mental health, we are partly responsible for thinking we could do it alone. We can't, we need to really collaborate with other agencies like housing. This isn't just a department of mental health issue; it's a [statewide] issue. With unemployment, etc., we need to look statewide and we need to do it together. We need to create opportunities for people to go back to work. In addition, education needs to be more informed about mental illness, especially the leaders so they can teach students about signs and warnings, so

they can go and get help early on—this could reduce suicide. I am also concerned in terms of professionals—social workers, psychologists, and psychiatrists—who go to school, and they are told that they can't talk about their own history with mental illness. For instance, if I went back into education, I might not get a job. States need to look at access to care in rural areas. I grew up in Montana and I know that in Montana there is trouble even recruiting a psychiatrist to go there. We need to do more to attract professionals to rural areas and also we need to look at how we can offer other options. Another thought is culturally competent care. This is a very important issue for states, especially in the state hospitals. This hasn't been paid attention to, nor has spirituality.

Lane: I would really encourage that NASMHPD and other stakeholders look to NAC/SMHA and the office of consumer affairs directors to work cooperatively with the commissioners to help drive these goals forward. They can do this by e s t a b l i s h i n g networks with NAMI and other s t a t e w i d e organizations and stakeholder bodies and really get a s e q u e n t i a l , systematic way to accomplish the goals. One of the projects that caught the attention of the NAMI consumer council is the concept of a database of consumer-operated services and supports that is nationwide, organized by state, plus cross-referenced by treatment setting. The whole idea of being able to catalogue what's out there and mobilize folks because you've got that level of information on resources that are available in local communities is amazing. It will also help us identify where there are gaps. I think it's great that some states have ample consumer-run services, but there are many areas where there is nothing. Those are the areas that NAMI would like to focus on helping develop capacity for starting up self-help organizations and entities, especially in rural areas. I think

this will also help make consumer run services more reflective of culturally diverse communities. I'm really hoping that all of the report and the goals will be a catalyst for unprecedented collaboration across the consumer/survivor movement spectrum. This is about transforming the mental health system. The only way to have this happen is for people to do the work in the community, roll up their sleeves, and apply the work needed to transform. This will make the system better.

McKinney: NASMHPD should sponsor a community-level version of the toolkit [discussed under Question #4] so people can talk about issues. It should be free, and people can help each other with it. The toolkit could tell you how not to stigmatize yourself, how to understand that you are not a bad person, that you are not harmful to society. It could help take the shame and the blame and the guilt away from you, and then you could more easily talk with other people about mental illness. NASMHPD could work with the states to create a prototype, then each state could alter it for their v a r i o u s populations. NASMHPD could also help build some media up about the discussion day and the toolkit and

"I'm really hoping that the report and its goals will be a catalyst for unprecedented collaboration across the consumer/survivor movement spectrum."

present them at the same time. It could be like a "Take your daughter to work day." It could be "Talk about mental illness day." The product has to be simple and catchy. Consumers are waiting for something to do to help themselves and others, and this would be a great effort for them. This is the kind of thing that could really help the little person, more than the grand ideas. We are looking for something free, something catchy, gimmicky, that people who are willing to talk about mental health can go out and talk about it with the help of this day and this toolkit. This would be especially helpful for people who are trying to assimilate back into the community. The

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recommendations of the Commission's final report."

A major push of the transformation effort is highlighted in Goal 2, *Mental Health Care is Consumer and Family Driven*. "The intention of the Commission is to ensure that all levels of public mental health have consumer and family needs at the basis of decisions that are made," said Curie. "The best ways are to directly involve consumers and family members in focus groups and advisory committees, to use data that is derived from consumer perspectives and family experiences, and to look at outcomes to hold ourselves accountable. There needs to be a process put into place where consumers and family members truly are the architects of their life recovery plan," he said. "The question for each state is How do you assure that each individual with SMI or SED has a life recovery plan that they not only own, but they can also manage? It's important at the federal and state level to make decisions to ensure that this goal will be realized."

"If mental health care is to be consumer driven," Power added, "consumer advocacy groups will be at the center of the transformation effort. Their voice, their engagement with us is the most important factor to making the kind of system change that is necessary. We are going to be using the consumer energy to

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toolkit effort would give them something to do so they could help. It would be a great first job back into the larger community.

Powers: One thing that is mentioned in the final report is telehealth and e-technology for rural areas. This is a very important way to reach out to people who would not be otherwise served. Electronic services for mental health are better than none at all. I think that in order to serve people in rural areas, states should consider this. There just aren't enough

make this change," she said. The federal government is also interested in working with the private sector during the transformation efforts. "We need to have the private sector engaged, to get the message into the groundwater of our society. I see engaging private sector providers, the media, and businesses in this effort," said Curie.

Despite their optimism for the potential of this transformation movement, both Curie and Power acknowledged the many barriers to the effort. "We need to build a new belief system because in our society today there is a systemic barrier, a cultural barrier, and a historic barrier," said Power. "Despite the fact that we have interventions, and that treatment works, people are still not getting it. Mental health is too separate from physical health. In addition, we have the stigmatization of mental illnesses themselves. Another barrier is that according to the Surgeon General's report, by the time people recognize that they might have a mental illness, they have already waited several years before seeking treatment. This isn't the case for physical health problems. That time without proper care is critical," she said. "Another barrier is despite the clamor for change that I hear across the nation, it's hard for people to change the status quo. I think this will have to be overcome through energy and a collective will."

"The major barriers that I would mention are stigma and attitude," said Curie. "Stigma, which President Bush identified early on, is a barrier to effective

psychiatrists and other mental health professionals in those areas. In general I was very impressed with the comprehensive nature of the report and I think it's a great start to have people at this level work to help people with mental illness. In the report, the commissioners emphasize the reduction of restraint and seclusion [SAMHSA Administrator] Charles Curie instituted a national call to action on reducing seclusion and restraint and this report also calls for a reduction. I don't think you can underestimate how an effort at the federal level can help reduce these practices and reduce stigma. ◆

care, because individuals won't seek care, and because of the bias against mental health and/or the lack of understanding about mental illness gets in the way of progress. Specifically, we need to be sure that public officials who are not in the mental health arena become more willing to focus on stigma as an issue that needs to be dealt with—the field of mental health is fraught with misconceptions."

Both Curie and Power confirmed their faith in NASMHPD as a prime partner in the transformation effort. "NASMHPD is the organization for working with state mental health authorities. I see NASMHPD as the appropriate and well-placed vehicle for dialogue on these issues, and NASMHPD is also an agent for the federal government to provide technical support and communication with states on these issues," said Power.

As for how states can work best with SAMHSA to begin or continue a transformation effort, Curie and Power listed some direct advice.

- ◆ Stay involved with the associations, such as NASMHPD. "They play a critical role of ensuring the transfer of knowledge and communication from the federal level to the state level," said Curie.

- ◆ Work with CMHS during the creation of potential templates for a state mental health plan.

- ◆ Contact SAMHSA with a) technical assistance and resource needs, and b) a listing of identified barriers to the transformation effort.

- ◆ Ensure the involvement of consumers and family members, providers, and local authorities at all levels. "These are essential responsibilities of each state," said Curie.

While the interests of the states may be more closely aligned with the interests of the federal government than at any time in recent history, much of the work to transform the public mental health system still lies ahead. According to Curie and Power, the time is now for states to work with the federal government to see that those interests are met on behalf of public mental health consumers nationwide. ◆

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legislation to implement the New Freedom Initiative Demonstration proposal on community-based alternatives for children in psychiatric residential treatment facilities. This would enable CMS to develop reliable cost and utilization data to consider permanent authority for a home and community-based waiver as an alternative to removing children from the community and placing them in residential care. The Commission also recommends technical assistance to states and communities to develop strategies for financing and developing a more comprehensive array of community-based services and supports.

Provision of Screening, Services, and Supports Where the Children Are (from Goal 4) will enable earlier identification and intervention for children. Development proceeds rapidly in children and emerging neurobiological research indicates that earlier intervention can influence the developmental trajectory and later outcomes for the child (Shonkoff & Phillips, 2000; National Advisory Mental Health Council Workgroup on Children and Adolescent Mental Health Intervention and Deployment, 2001). The Commission strongly recommends screening for emotional and behavioral disorders and co-occurring mental health and substance abuse disorders in natural settings where children are, such as in schools and primary care settings, with full recognition of the need for privacy and confidentiality for these children and their families. With suicide as the third leading cause of death in adolescents, screening for depression and suicide and connection to treatment becomes imperative.

This is reiterated in **Promotion of a National Strategy for Suicide Prevention (from Goal 1)** with public education initiatives targeting adolescents. Also recommended is screening and treatment of youth in high-risk settings where there are high rates of mental disorders, such as entry to child welfare and juvenile justice. Given the

disproportionate representation of youth of color in these systems, earlier intervention may address persistent disparities in access to services for these populations. To support this recommendation, the Commission calls for interagency collaborations at the federal, state, and local levels across child-serving agencies for collaborative planning and funding of these efforts.

These recommendations expand the mandate of the Commission beyond children with serious emotional disturbances to include those at-risk and those as yet unidentified. This aligns with

The Commission strongly recommends screening for emotional and behavioral disorders and co-occurring mental health and substance abuse disorders in natural settings where children are, such as in schools and primary care settings.

a public health, early intervention approach based on research indicating that early detection and treatment may substantially shorten and lessen the disabling course of mental health problems.

Promotion of Mental Health in Young Children (from Goal 4) builds on the evidence that untreated mental health problems in children ages 0-6 severely impact school readiness and lead to poor developmental trajectories. Emerging neuroscience reveals the impact of environmental factors on brain development and early psychosocial behavior and makes the compelling argument that early detection, assessment, and treatment can prevent mental health problems from worsening (Rintoul, 2003).

The Commission calls for a national focus on the mental health needs of young children that will include workforce training with a particular focus

on primary health care providers and early social-emotional “check-ups,” eliminating barriers to coverage, and building on care coordination such as Part C of the Individuals with Disabilities Education Act.

Use of Evidence-based and Emerging Best Practices (from Goal 5) will ensure that children receive the best quality of care. Despite advances in the treatment of specific conditions and emerging research on the effectiveness of community-based interventions, the dissemination and implementation of these interventions in the field occurs at a painstakingly slow pace. Consequently, children may not be receiving the most effective care.

The Commission believes that a significant step in transforming outcomes for children is the provision of evidence-based, demonstrably effective care by a workforce trained in these interventions. The Commission recommends more rigorous implementation efforts and partnerships, use of Medicaid waivers to implement evidence-based practices, engagement of private sector payers to support evidence-based practices, and ongoing efforts to develop the evidence for field-generated promising practices.

A Comprehensive State Mental Health Plan (from Goal 2) should designate a special focus on children that would incorporate the recommendations discussed above, which taken together, may begin to transform a state’s approach to delivery of services, facilitate new partnerships among various state child-serving agencies—including the Medicaid agency—private payers, and families. For children and families, these plans will have an important impact on reducing fragmentation of services and financing. By reaching beyond the traditional state mental health agency to include health, education, child welfare, juvenile justice, child care, recreation, and early intervention, these plans will address the full range of services and supports that children and families need.

A state plan will also address disparities in access and outcomes for

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youth of color and designate program performance measures targeting **Elimination of Disparities (from Goal 3)**. The underlying premise for these plans is that as states increase their levels of interagency coordination, federal agencies will provide greater flexibility in how funds may be used. Increased flexibility from the federal level (e.g., blending funds, streamlining reporting requirement, etc.) will be in exchange for greater accountability and improved outcomes at the state level.

A Preview of the Issue Paper. In addition to the final report, the Commission developed Subcommittee reports on specific topics. The issue paper on Children and Families takes a more in-depth look at the mental health services for children and provides an extensive “blueprint” for service delivery. The paper provides a two-pronged approach focusing on children with serious emotional disorders as well as delineating a public health approach for promoting, preserving, and restoring mental health for all children.

A comprehensive set of policy options addresses nine problem areas for children’s mental health: 1) fragmentation in responsibility and funding; 2) lack of family partnerships and family support; 3) unmet need and disparities in access; 4) gaps in services; 5) gap between what we know and what we do; 6) lack of a prepared workforce; 7) lack of focus on prevention and early intervention; 8) persistence of stigma; and 9) lack of accountability and quality improvement.

Specific implementation strategies with designated vehicles, agencies, and resources are clearly delineated. Taken together, these two reports provide a strategy for transforming mental health care for children in America. ♦

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