

# Mental Health Liaison Group

March 2003

To Chairman Hogan and Members of the New Freedom Commission on Mental Health:

As national organizations representing consumers, families, advocates, states, counties, and communities, we have unique perspectives and deep concerns about public mental health services in this country. While our missions differ, we have long worked together to advocate for profoundly needed changes in the public mental health system and are pleased to submit for the Commission's consideration the attached series of papers containing policy recommendations.

We are pleased to submit for the Commission's consideration the attached series of papers containing policy recommendations. The papers, organized by issue area, set forth both administrative and legislative recommendations. These recommendations address many of the broad themes on which you have heard testimony and offer our best judgment for specific, attainable policies that can be implemented to achieve the goals set forth by the Executive Order of April 29, 2002. The papers cover the following topics:

- Employment Services and Disability Benefits
- Children and Adolescents
- Co-Occurring Mental Health and Substance Abuse Disorders
- Criminal/Juvenile Justice and Mental Health
- Evidence-Based Practice and Research
- Housing
- Workforce Development
- Medicaid
- Medicare

Meeting the needs of children and adults with mental health disorders requires that they have access to a comprehensive system of care – including a range of community-based services from early intervention through acute inpatient crisis care – which provides mental health services that are affordable, culturally competent, appropriate, and of high quality. Our recommendations are designed to achieve this goal. But they are also borne of painful recognition of the condition of public mental health, which you have cogently described in the Commission's Interim Report to the President.

In the interest of brevity and focus, the papers do not contain background or contextual information. Although we would be pleased to amplify and expand on our submission at your request, the problems we propose you address and the rationale underlying our recommendations are in substantial part already reflected in the Interim Report, as well as in the extensive record of testimony the Commission has already taken. It is our hope that our work will provide useful guidance as you move toward the development of a final report that can be a beacon and blueprint for the future.

## **Groups Endorsing the Mental Health Policy Recommendations**

American Academy of Child and Adolescent Psychiatry  
American Association for Marriage and Family Therapy  
American Association of Children's Residential Centers  
American Association of Pastoral Counselors  
American Group Psychotherapy Association  
American Mental Health Counselors Association  
American Orthopsychiatric Association  
Bazelon Center for Mental Health Law  
Child Welfare League of America  
Children and Adults with Attention Deficit/Hyperactivity Disorder  
Federation of Families for Children's Mental Health  
International Association of Psychosocial Rehabilitation Services  
The International Society of Psychiatric-Mental Health Nursing  
National Alliance for the Mentally Ill  
National Association for Rural Mental Health  
National Association of Children's Behavioral Health  
National Association of County Behavioral Health Directors  
National Association of Mental Health Planning and Advisory Councils  
National Association of Protection and Advocacy Systems  
National Association of Psychiatric Health Systems  
National Association of School Nurses  
National Association of School Psychologists  
National Association of Social Workers  
National Association of State Mental Health Program Directors  
National Council for Community Behavioral Healthcare  
National Mental Health Association  
National Mental Health Awareness Campaign  
Suicide Prevention Action Network USA  
Treatment and Research Advancements Association for Personality Disorder

## **EMPLOYMENT SERVICES AND DISABILITY BENEFITS**

### **Social Security Disability Programs**

- SSDI beneficiaries lose their entire benefit if they earn even one dollar over the allowable limit of \$740 a month. Consequently, people on SSDI are forced to limit the hours they work, turn down raises, and refuse better paying jobs. Congress can invest in the recovery of persons with mental illnesses by changing the SSDI benefit to resemble SSI, where a person loses one dollar in SSI benefits for every two dollars they earn. This will encourage beneficiaries to enter or reenter the workforce without fear of losing immediate access to income supports and medical benefits.
- Many beneficiaries who work accrue thousands and sometimes tens of thousands of dollars in overpayments through no fault of their own because the Social Security Administration (SSA) does not track and record earnings. SSA must adopt an income reporting system so that checks are not sent to beneficiaries who have reported that they are ineligible due to work. Until then, SSA should be prohibited from collecting overpayments from beneficiaries who follow the rules and report earnings.
- Individuals with mental illnesses and other disabilities have a great deal of difficulty getting accurate information from SSA about rules pertaining to work incentives and return to work. SSA should fully implement the Employment Support Representative Program, which is designed to provide beneficiaries with accurate information about work and work incentives. Further, Congress and the Administration should significantly increase funding for the Benefits Planning, Outreach, and Assistance Program that is a part of the Ticket-to-Work law.
- Under the Ticket-to-Work program, a rehabilitation provider is paid a share of the savings that accrue because a person is no longer receiving cash benefits. Under the SSI program, benefits are reduced one dollar for every two dollars earned by the beneficiary. But SSA doesn't make payment to providers until all SSI benefits have ended, even though the person may have offset earnings by fifty, seventy-five or even ninety percent of their SSI check. SSA should change the payment system to providers so that providers get a partial payment for savings that occur because a working SSI beneficiary partially offsets their SSI benefit due to work. This will provide a strong incentive to rehabilitation providers to participate in this important program.

### **The State-Federal Vocational Rehabilitation Program**

- The Federal-State Vocational Rehabilitation program (Title I of the Rehabilitation Act) has generally been ineffective in addressing the needs of individuals with serious mental illnesses. The federal resources funding VR that are intended to serve individuals with mental illness should be extracted and applied to a program that is specifically designed to meet the unique needs of the individuals with mental illness.

If this recommendation is not approved, we propose the following recommendations:

- Significantly increase funding for the Supported Employment Program under Title VI-C of the Rehabilitation Act. Additionally, the Rehabilitation Services Administration (RSA) and

the Center for Mental Health Services (CMHS) should develop and expand long-term supports and supported employment opportunities for people with mental illness.

- Increase RSA technical assistance to states on best practices in providing services to persons with mental illnesses, including hiring counselors who specialize in the employment of persons with mental illness, adopting weighted closure systems, supporting consumer-run businesses and hiring consumer peer employment specialists. The RSA must also take a more active role in evaluating and monitoring the adoption of these best practices by states.

*Department of Labor Workforce Programs*

- SSA, RSA, CMHS, and the Department of Labor should work closely to coordinate services for persons with mental illness.

## CHILDREN AND ADOLESCENTS

- **Improve access to and coordination of mental health services.**

- Administrative Measures

- The President should issue an executive order establishing an interagency body to foster greater coordination, and collaboration and joint financing, across the numerous federal programs with responsibilities for, or related to, children's mental health. Its focus should be on developing systems-collaboration in the delivery of community-based mental health services. The order should require the pertinent agencies to coordinate their respective efforts, beginning with development of overarching, common policy goals, operational plans, and common outcome measures. The order should direct the agencies to revise rules that impede furthering policy goals and seek legislative change, if necessary, to overcome those barriers.
- The President should issue an executive order encouraging greater coordination and collaboration between, and joint financing of existing Federal programs, to promote mental health screening and early intervention and treatment through the schools with the stated aims of averting development of serious emotional disorders, improving academic performance, preventing youth violence, preventing suicide and meeting the range of treatment needs of schoolchildren.
- CMS should establish policy to ensure that states fully use Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services.

- Legislative Measures

- Establish a program to support the establishment and provision of integrated services as alternatives to out-of-home placement of children with mental or emotional disorders. Administered by SAMHSA (in consultation with the Office of Juvenile Justice and Delinquency Prevention, Department of Education, and other pertinent agencies within HHS), the program would provide for planning and "front-end" funds to states and communities to develop and implement new financing mechanisms to establish and operate comprehensive home- and community-based services and supports to children with mental or emotional disorders and their families. Grantees would need to demonstrate a plan for sustaining service capacity through the pooling of funds from multiple systems (or otherwise redeploying and linking different funding sources).
- Authorize the Department of Education, in consultation with the Substance Abuse and Mental Health Services Administration, to make grants to states, other units of government, and private nonprofit organizations to support the provision (in schools and other educational settings) of (1) screening and other assessments; (2) early intervention, crisis intervention, and mental health services to children with, or at risk of, mental, emotional or behavioral disorders; and (3) professional development and training of staff. Grant applicants must demonstrate broad collaboration of

parents and all relevant local agencies and organizations in the application for, and administration of, a grant.

- Establish a five-year matching-grant program in SAMHSA, in consultation with the Health Resources and Services Administration, to assist community health centers to provide mental health screening for pre-school children in primary care settings, and provide referral services to – or early intervention services in collaboration with – community mental health centers and other appropriate providers. The program would employ appropriate screening tools to assess at-risk children otherwise eligible for care by community health centers, and would encourage formal linkages between those centers and community mental health centers (or other appropriate providers) to assure continuity of care.
  - Require explicitly that grantees under the Comprehensive Community Mental Health Services for Children’s Program provide integrated services to address co-occurring mental health and addiction disorders.
- **Treatment for youth in or at risk of contact with the juvenile justice systems.**
    - Administrative Measure
      - The Department of Education and other relevant federal agencies should issue guidelines, similar to those recently released by the Office of National Drug Control Policy, that urge school administrators to treat and counsel high school students who are disruptive or use drugs and show signs or symptoms of mental or emotional disorder, rather than suspending, expelling, or turning them over to juvenile courts without treatment.
    - Legislative Measure
      - Provide grants that would ensure mental health screening for all juveniles entering the juvenile justice system, followed by, if appropriate, diversion and treatment. [See Mental Health Juvenile Justice Act (H.R. 2198 and S. 1965)].

## **CO-OCCURRING MENTAL HEALTH AND SUBSTANCE ABUSE DISORDERS**

- Amend section 1956 of the Public Health Service Act to clarify that the mental health and substance abuse block grants may be used to fund integrated treatment services for individuals with a co-occurring mental health and substance abuse disorder and delete language (“ . . . and can be tracked for accounting purposes.”) that reinforces separate use of block grants and confuses the field. Recommended language: “States may use funds available for treatment under sections 1911 and 1921 to provide integrated treatment services for persons with co-occurring substance abuse and mental disorders as long as funds available under such sections are used for the purposes for which they were authorized by law.”
- Amend SSI to allow individuals found to be disabled due to substance abuse to be eligible for Medicaid coverage.
- SAMHSA should provide written policy guidance to the field describing how the block grants can both be used to fund integrated treatment services to adults with serious mental illness and children with severe emotional and behavioral disorders. To help implement the guidance, SAMHSA should provide technical assistance to states to ensure that mental health and substance abuse block grant reporting requirements do not create a barrier that prevents states from using block grant funds to establish integrated programs.
- ONDCP and HHS should convene a forum to promote awareness of the needs of individuals with co-occurring disorders and to encourage policies designed to meet their needs.
- Fund new rigorous research projects on integrated treatment.

## **CRIMINAL/JUVENILE JUSTICE AND MENTAL HEALTH**

- Federal grants, jointly administered by the Departments of Health and Human Services and Justice, should be provided on a national scale to state and local governments to encourage collaboration among a broad array of agencies – including housing, mental health, substance abuse, education, law enforcement, courts, and corrections – to create programs and policies that will maximize diversion from the criminal and juvenile justice systems of adults with serious mental illness and juveniles with emotional or behavioral disorders who have been accused of crimes and for whom voluntary mental health treatment is a reasonable alternative to criminal sanctions.
  - Grantees could use funds to establish:
    - Pre-arrest law enforcement diversion programs.
    - Mental health courts, and other post-booking diversion programs.
    - Community re-entry programs.
    - Training for mental health and criminal and juvenile justice professionals.
  - Individuals diverted under such programs should receive a full array of community-based mental health services, including: crisis intervention, case management, medication and medication management, suicide prevention, and, when appropriate, integrated mental health and substance abuse treatment services. Adults in particular must have access to assertive community treatment, psychiatric rehabilitation, and peer support services. Juveniles must receive multi-systemic therapy or wraparound services, mentoring, and family support services.
  - To the extent practicable, programs should assist diverted individuals with housing, education, employment, health care, and benefits (such as disability income, disability insurance, and Medicaid).
- The Center for Medicare and Medicaid Services should issue a State Medicaid Director letter clarifying that Medicaid eligibility cannot be terminated during incarceration (unless due to loss of some other benefit, such as SSI) for either juveniles or adults.
- Ensure reinstatement of SSI and SSDI benefits for those released from correctional facilities.
  - Amend SSI law to permit suspended benefits to be payable on day of release; SSA would then confirm continued financial eligibility of individual.
  - Create provisional presumptive eligibility benefit for individuals whose SSI has been terminated, pending SSA review of their claim and provided a health care professional certifies that they continue to have a disability.
  - Suspend all continuing disability reviews for SSDI recipients who are incarcerated in correctional facilities.

## **EVIDENCE-BASED PRACTICE AND RESEARCH**

- Federal and state agencies should use the definition of Evidence-Based Practice adopted in the Institute of Medicine Report, Crossing the Quality Chasm (2001): “Evidence-Based Practice is the integration of best research evidence with clinical expertise and patient values.” This definition balances 3 essential components of state of the art practice: the best science-based evidence; the skills and judgment of health professionals; and the unique needs, concerns and preferences of the person receiving services.
- National Institute of Mental Health needs to identify mechanisms to:
  - Rapidly identify promising practices for adults with severe mental illness and children with serious emotional disorders.
  - Prioritize these promising practices for research awards
  - Develop service research strategies for use with complex, real world populations (for instance adults with co-occurring mental illness and substance abuse disorders, receiving multiple medications) and ensure 15% of the agency’s research portfolio supports this area of services research.
  - Disseminate information on evidence-based practices to other federal and state agencies that develop policy and funding for services, as well as to the mental health community.
- The Substance Abuse and Mental Health Services Administration needs to receive authorization and funding to continue multi-site demonstration investigations that target high priority services areas.
- The Agency for Healthcare Research and Quality is the government agency mandated to research the delivery of healthcare services, but historically little attention has been given to mental health services. It needs to substantially increase its attention to services research for adults with severe mental illness and children with serious emotional disorders.
- The National Institute of Disability and Rehabilitation Research needs to aggressively pursue services research for adults with severe mental illness. In the recent past, much of the agency’s research portfolio has concentrated on services common to all people with disabilities. Unfortunately, much of this research is not useful for adults with severe mental illness.
- The Center for Medicaid and Medicare Services needs to develop mechanisms to:
  - Incorporate these services into Medicare and Medicaid in a timely fashion. New mental health services have not been incorporated into Medicare since 1992, and the reimbursement mechanism is not in place for a decade of promising practices.
  - Regularly update state Medicaid agencies on new evidence based practices for potential inclusion in state Medicaid plans.

## **HOUSING**

- **Housing as an issue of poverty**

While alleviating poverty for non-elderly adults with severe mental illnesses is far beyond the scope of the Commission’s mandate, there are several concrete steps that can be made by HUD to address the affordable housing crisis for consumers whose sole income support is SSI cash benefits. These include:

- Promoting greater targeting of HUD’s programs (particularly HOME) toward development of rental housing that serves extremely low-income households (those at 30% of median income and below).
- Allowing greater discretion for housing authorities to “project-base” or “sponsor base” Section 8 tenant-based vouchers and allow non-profits to operate property-specific waiting lists.
- Urge Congress to emphasize rental production and extremely low-income targeting as part of any new affordable housing production program.

- **Discrimination, NIMBYism, and problems with the affordable housing system**

- Direct the Office of Public and Indian Housing at HUD to issue guidance to all housing authorities receiving rental vouchers for people with disabilities tied to “elderly only” designation to ensure that they remain directed to non-elderly people with disabilities upon turnover.
- Grant the HUD Office of Fair Housing Equal Opportunity (FHEO) oversight authority for approval of all public housing Allocation Plan submissions.
- Direct HUD to issue regulations implementing the assisted housing tenant preference provisions of Title VI of the Housing and Community Development Act of 1992.
- Direct HUD to complete its Section 504 compliance process and develop a plan to meet its pre-existing goal to ensure that HUD programs affirmatively further fair housing.

- **Maintaining current housing resources**

- Applaud HUD for its most recent initiative to address chronic homeless.
- Direct HUD to develop a long-term plan for stable funding for renewal of expiring rent subsidies under the Section 811 program and the permanent supportive housing programs under the McKinney-Vento Homeless Assistance Act (Shelter Plus Care and SHP).
- Direct HUD to continue the 30% permanent housing set aside and 25% local service match requirement within the McKinney-Vento Homeless Assistance Act.

- **Public mental health system and housing retention**

- Direct HUD and the SAMHSA to develop a set of evidence-based best practice guidelines for housing-related supportive services for public mental health agencies.
- Direct the Centers for Medicare and Medicaid Services to develop guidance for the states on Medicaid financing of supportive services in permanent supportive housing.

## **WORKFORCE DEVELOPMENT**

- **Establish a Public Mental Health Leadership Development Program**  
SAMHSA should partner with local and state public authorities and private sector entities to create a leadership development program that would provide mental health professionals with opportunities and incentives to enhance their skills and play a role in creating and mapping the future of public mental health services in this country.
- **Update accrediting standards for professional schools and training programs**  
SAMHSA, in collaboration with HRSA, and in consultation with appropriate accrediting bodies should assess and update the quality of mental health professions' practice and education to ensure that evidence-based practices are being taught and incorporated into practice in the field in terms of philosophy, practice, and standards.
- **Re-define and expand the Mental Health Professional Shortage Area Designation Program**  
Legislation should be enacted that re-defines and expands the Mental Health Professional Shortage Area Designation Program. The existing mental health professional shortage designation program should be expanded to include service within any public sector agency providing services to Medicaid beneficiaries. This expansion of the definition would take into account the fact that a given area may have ample providers on a per capita ratio but not have practitioners who are willing to serve individuals who are in the public system. The existing mental health shortage designation program needs to be broadly promoted and used as a recruitment tool especially with students who are ethnic minorities in graduate schools and residency programs. In this and other workforce development efforts, special attention must be given to the challenges faced in inner city, rural and frontier areas.
- **Establish or expand scholarships, loan repayment programs, training grants and graduate medical education specialty training support for children's mental health professions.**
- **Expand or establish loan repayment, scholarship, and grant programs**  
Legislation should be enacted that re-institutes historic federally-funded scholarship programs to increase the number of individuals, particularly those of ethnic minorities, who attend professional schools in medicine, social work, psychology, nursing and marriage and family therapy. Such legislation should establish a grant program to graduate schools to facilitate the development of internships and fieldwork placements in the area of public mental health. A grant program should also be developed for public sector agencies to provide tuition reimbursement programs/work release programs to allow existing paraprofessional staff to return to graduate school to receive graduate degrees in social work, psychology nursing, and marriage and family therapy.
- **Reauthorize and expand the J-1-Visa Waiver Program**  
The Federal government should administratively continue and expand the J-1 Visa Waiver program in order to increase the number of mental health professionals in underserved areas.

## **MEDICAID**

### **Community Services**

- Amend Medicaid law to cover intensive community mental health services. This would allow states to reimburse for comprehensive programs that provide services that normally fall within a broad array of services, such as targeted case management, clinic, rehabilitation and personal care. Bipartisan legislation introduced in both houses of Congress would accomplish this (see H.R. 2364 and S. 2072, introduced in the 107<sup>th</sup> Congress).
- Issue a State Medicaid Director Letter clarifying psychiatric rehabilitation rules. Such policy guidance would also need to ensure that services now covered in at least a third of the states are recognized in federal rules. At a minimum, these services include: skills-training to enable individuals to maintain their living situation; educational placement or employment; assertive community treatment; peer-provided services; intensive outpatient programs, intensive in-home services for children; school-based; after-school and summer day treatment programs; mentors and multi-systemic therapy for children and youth.
- Amend Medicaid to include residential treatment centers as institutions for purposes of home- and community-based waivers (Section 1915(c)).
- Create a template so states can provide community-based services for adults at risk of placement in Medicaid-covered institutions (psychiatric hospital, nursing home or IMD) that specifically addresses unique issues of a home and community based waiver for a person with mental illness. For example, the institutional eligibility categories have special rules for this population and service needs may differ from those with developmental disabilities or who are elderly. Secondly, as specified for these other populations in the State Medicaid Director letter (SMDL #02-008) dated May 9, 2002, specifically cover for individuals with mental illness: transitional costs from an institution to community living such as discharge planning; one-time set up expenses for individuals making a transition from institution to their own home, such as security deposits, essential furnishings and moving expenses; set up fees or deposits for utility or service access (e.g. telephone, electricity, heating); and health and safety assurances (pest eradication, allergen control or one-time cleaning prior to occupancy).

### **Eligibility Rules**

- Issue a State Medicaid Director letter clarifying that Medicaid eligibility cannot be terminated during incarceration (unless due to loss of some other benefit, such as SSI) for either juveniles or adult.
- Provide states with the option of allowing families of children with disabilities to buy into Medicaid in order to allow these children access to the intensive rehabilitative community services only available through publicly-funded systems.
- Amend federal rules to permit individuals residing in an IMD to receive Medicaid-funded physical health care services on- or off-site.

## **Children's Services**

- CMS should permit and encourage states to switch to the Zero-to-Three assessment system for children younger than four. The Zero-to-Three assessment system is increasingly recognized as a more appropriate system for determining the need for mental health treatment. Very young children need to be assessed for developmental delay and inappropriate behaviors or social interactions. Neither DSM nor ICD are well adapted for infants and toddlers aged 0-3.
- Provide states with greater flexibility to cover services to families of children with mental disorders. Children need to be treated in the context of their family unit. Current Medicaid rules regarding directing the delivery of all services to the identified "patient" hamper states ability to provide good care.

## **Administrative Issues**

- Require CMS and states to report cost and utilization data for mental health services.
- CMS should conduct a study of why individuals who are eligible under their state plan do not have access to services – investigate issues of lack of appropriate billing codes, inappropriate diagnostic requirements and/or providers not available.

## **MEDICARE**

Medicare does not cover many of the evidence-based services described in the Surgeon General's Report on Mental Illness. Also, despite much innovation among the states in their Medicaid programs, Medicare covers none of those innovative mental health services that most states routinely offer through Medicaid.

Substance Abuse and Mental Health Services Administration (SAMHSA) data on utilization and cost of mental health and substance abuse inpatient and outpatient services for Medicare and state Medicaid coverage in Michigan, New Jersey, and Washington reveals that Medicare's lack of outpatient services and the discriminatory 50/50 co-pay for outpatient mental health services is driving up Medicare inpatient hospitalization. Expanding outpatient services and eliminating the co-payment disparity would reduce hospitalization and save billions of dollars annually.

### **Recommendations**

- Congress should reform Medicare to cover the following services that states typically offer through Medicaid—psychosocial rehabilitation, assertive community treatment, intensive case management, crisis residential care, and individual providers who are licensed by their respective state to provide behavioral health services.
- Medicare should be amended to end the discriminatory 50-50 mental health outpatient co-pay and make it equal to the 80-20 co-pay that Medicare requires for all other health services;
- Medicare should be amended to cover prescription drugs, including the full array of psychotropic medications.