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ABSTRACT

This theme issue of a bulletin on family support and children's mental health focuses on managed care and the impact on children who are in need of mental health services. Articles include: "Private Sector Managed Care and Children's Mental Health" (Ira S. Lourie and others); "Just What Is Managed Care?" (Chris Koyanagi); "Managed Behavioral Health Care and Family Involvement: The Arizona Experience" (Teri Sanders); "Georgia Family Organization Plays Key Role in Delivery of Children's Mental Health Services" (Sue Smith); "Montana's Managed Care Gold Rush" (Barbara Sample); "Philadelphia County Develops Family-Friendly Behavioral Managed Care Plan" (Estelle B. Richman); "Consumer Involvement in Managed Care" (Bazelon Center for Mental Health Law); "Ending Discrimination in Health Insurance through Federal Law: A Children's Mental Health Perspective" (Michael M. Faenza); "Principles of Family Involvement in the Development and Operation of Managed Health and Mental Health Care Systems for Children and Youth" (Federation of Families for Children's Mental Health); "Operationalizing Cultural Competency in a Managed Care Environment" (Josie T. Romero); "A System in Transition: CASSP Principles Revisited" (Judy Robison); "Managed Care in Evolution: One Family's Experiences" (Teri Sanders); and "The Impact of Children's SSI Program Changes in Welfare Reform" (Bazelon Center for Mental Health Law). Managed health care resource materials are also listed. (CR)

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# FOCAL POINT

A NATIONAL BULLETIN ON FAMILY SUPPORT & CHILDREN'S MENTAL HEALTH

## FAMILIES, MANAGED CARE, & CHILDREN'S MENTAL HEALTH

### PRIVATE SECTOR MANAGED CARE AND CHILDREN'S MENTAL HEALTH

The federal Child and Adolescent Service System Program (CASSP), launched in 1984, has been an important contributor to the movement to make major changes in the way services are provided to children with severe emotional disorders and their families. The principles underlying CASSP call for community-based systems of care that are comprehensive and emphasize coordination among child-serving agencies, service delivery in the least restrictive environment, full involvement of families, and cultural competence. These principles have been widely accepted in the worlds of child welfare, child mental health, juvenile justice and special education. The reform efforts have led to a movement to restructure these four major child-serving capacities into a single community-based, family-focused, culturally competent interagency system of care (5). This systematic approach has encouraged a reduction in psychiatric hospitalization and residential treatment with an accompanying shift toward in-home, community-based modalities that focus on utilizing family strengths, family preservation, family support, and wraparound intervention strategies (1, 3, 4).



Over the last decade the system of care concept and philosophy have become the prevailing public service delivery ideology for children and adolescents with severe emotional disorders and their families. This shift has been true only with respect to long-term care for children and youth with the most serious problems and needs, and has been limited primarily to the public sector. For those children and families whose care was supported with private sector dollars in the form of health insurance, the vast majority of mental health services provided were still being offered in a traditional mode, with services limited to inpatient and outpatient modalities, delivered without a systematic approach. Families were being denied the more family-friendly, strengths-based, community-based interventions available in the public sector.

By 1992, several private mental health provider agencies were describing the development of services that appeared similar to those used

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### JUST WHAT IS "MANAGED CARE"?

In both the public and private sectors there is increasing emphasis on new ways to organize, deliver and finance mental health care. More and more consumers and families find themselves dealing with new systems—health maintenance organizations (HMOs), preferred provider networks (PPOs), primary care case managers or point-of-service plans. Even traditional insurance plans now frequently use utilization reviews to determine whether a particular service is necessary. The overall term for these new approaches is managed care.

Instead of allowing consumers open access to any health service (within the limits set by an insurance policy or public program), managed care systems have a mechanism to constrain unnecessary use of services and to ensure that each person's care is "appropriate" or "medically necessary." Managed care is a sharp contrast to the alternatives: a fee-for-service system, where the payor agrees to reimburse for specified services furnished to a covered individual, or a public grant program, that provides a pre-set sum of money for specified services but allows the provider agency to determine whom it has the capacity to serve.

The managed care industry often describes managed care as a system to ensure that each individual receives the right services at the right time in the right amount—no more, no less. But the term "managed care" encom-

*Continued on page 3*

#### SPECIAL FEATURE

Federal Mental Health Parity Law Enacted.

See pages 19 – 24.

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We invite our audience to submit letters and comments.

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## JUST WHAT IS "MANAGED CARE"? CONTINUED

passes so many different ways to do this that describing a system as a managed care system gives very little information about how it is really organized and how it operates.

Increasingly, managed care in the mental health system is taking the form of capitated payments for the provision of mental health and substance abuse services to a defined population, called behavioral health care. In these plans, a managed care entity—which can be either public or private, profit-making or non-profit—receives a set fee, known as a capitation rate, for each person it agrees to serve. The fee is paid either by an insurance company or employer, or by a family or individual. In a publicly funded program such as Medicaid, mental health or child welfare, the fee is paid by the state.

In return for the fee, the managed care entity agrees to provide specific behavioral and/or physical health care services. As a general rule, the managed care entity is paid the same capitation rate for each person, no matter how much the person uses the services. This is often described as "risk-based contracting," because the managed care entity assumes the financial risk of providing services beyond those paid for when that is necessary.

In the public sector, the extent of coverage under managed care is usually defined in a contract and will partly depend on the fee that the managed care entity receives. For example, a Medicaid managed care plan with a high capitation rate is likely to offer a broader range of mental health services than a plan with a lower capitation rate, and is likely to allow children and families to use these services more often.

As part of the contract, the managed care entity agrees to provide, when necessary, any of the covered services to any participating child and family, even if this results in costs higher than the capitation rate. Managed care entities, therefore, have in-

centives to control the use of services very closely. Sometimes this is done by limiting the kinds of services that physicians and other mental health professionals can offer a family.

Managed care plans have their own standards (called guidelines or protocols) to decide the type of benefit and level of care appropriate for each individual. The standards may limit the number of times a child or family can be seen or the length of time they can receive a service or support. To avoid losing money, a plan may not provide the services a family believes a child needs. Sometimes, a provider may even fail to speak frankly with families about the level of care needed, or may not make a referral to a specialist because it is against the policy of the managed care entity to do so. In such cases, it is important for families to understand how to appeal on behalf of their child.

Managed care entities often control costs by reviewing providers' decisions about treatment and services. Service providers may have to seek approval for certain services and the managed care entity will consider both the cost of the service and the child's need. This process is called utilization review.

There are different ways to provide behavioral health care in a managed care plan. Some plans are comprehensive and include physical as well as mental health services. Other systems "carve out" mental health services from other health care and provide them through a completely separate managed care plan. Some plans fall between these extremes, providing routine mental health care through the basic plan while covering treatment, services and supports for more severe or long-term mental health problems through either a separate managed care plan or the traditional fee-for-service system.

However the managed care plan is set up, managed care plans have a strong track record of saving money over the open-ended fee-for-service

approach. In addition, a managed care contract offers the purchaser—whether a company or a public agency—predictable costs. These factors are leading to rapid expansion of managed care, both in the private market and the public sector.

Mental health and other state agencies are now seriously planning and, in a few states, are actually using managed care systems. Many individuals who are covered by Medicaid already receive their services through managed care. Increasingly, state officials are talking about combining Medicaid, mental health, substance abuse and sometimes child welfare funds to develop an inter-agency managed care systems for children with mental, emotional or behavioral disorders.

A state that requires individuals who are eligible for Medicaid to join a managed care plan must have approval from the federal government. The federal Health Care Financing Administration (HCFA) allows states to waive (i.e., not follow) certain Medicaid requirements if it finds the state's managed care plan acceptable. When a state requests such a Medicaid waiver, it must solicit and take into account the opinions of concerned citizens, such as families and advocates for children with mental, emotional and behavioral disorders.

Managed care systems in some states operate through existing public-sector programs such as community mental health centers. In other states, private, for-profit managed care companies operate managed care systems on a contract basis for the states. Finally, in still other states, the decision about managed care may shift to counties or regional bodies.

When there is a contract with a private firm, the contract specifies: (1) who will be served; (2) what services will be provided; (3) how much money the managed care entity will receive for each adult and child enrolled; (4) the standards for evaluating the services; (5) what reports will



be produced; (6) how families can appeal decisions that they do not like; and (7) all other aspects of the managed care system. Managed care companies are required to do only what is spelled out in their contracts. Companies cannot be compelled to do anything that is not contained within their contracts—even if a particular course of action would clearly be good policy.

Where the public sector operates a managed care system, a public planning document should include the same description of how the system will operate.

Unfortunately, much of managed care emphasizes cost controls and

profit-making over quality care. Poorly run managed care can limit access to care and result in denial of necessary services and supports. Well-run managed care that is adequately funded should control health care costs while maintaining quality.

Child and family advocacy groups should not let the technical terms and aspects of managed care divert them from their goals. Discussion of managed care raises the same policy concerns about children's mental health that families and advocates have struggled with for years. The goals of a managed care system should be the same as the goals of any good public system.

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Chris Koyanagi

This article is based upon two Bazelon Center publications: *Managing Managed Care for Publicly Financed Mental Health Services* and *Managing Behavioral Health Care for Children and Youth: A Family Advocate's Guide*. Ordering information is provided on pages 32 and 33.

## PRIVATE SECTOR MANAGED CARE AND CHILDREN'S MENTAL HEALTH CONTINUED

in the public sector, including home-based, crisis intervention/stabilization, respite, and other hospital diversion modalities. The current study was undertaken for the purpose of demonstrating: (1) the degree to which this technology diffusion had occurred; and (2) the degree to which children, adolescents and their families whose care is supported by private resources were having their needs met in a systematic way.

### METHODOLOGY.

This study was designed as a descriptive study of a limited number of sites chosen to represent the state of the art in private systems of care. The stated purpose of the study was to: (1) identify systematic private sector models for delivering mental health services to children, adolescents, and their families; (2) describe such system models; (3) define the elements of those systems that can and should integrate with public systems; and (4) summarize the lessons to be learned from the experience of these systems.

The working definition of a private sector system of care that emerged is: (1) an array of services for children and adolescents with

emotional problems and their families; (2) offered to a population whose care is not primarily supported with public funds; and (3) provided either by an agency or group of agencies under a managed care contract with a health maintenance organization (HMO), preferred provider organization (PPO) or insurance company plan, or provided by an insurance or managed care provider company (by itself or through contracts with several agencies).

Providers of managed care organizations eligible for selection for the study:

- Must have a continuum of services available to a population of private mental health clients under a fee for service or managed care arrangement; that focus must be either aimed at hospital diversion and/or minimization of hospital stay and must have a focus on nonresidential services.

- Must have—or be moving strongly toward—an array of services that includes most of the following capacities available to the entire population served; including short-term hospitalization, day/partial hospital, therapeutic foster care, crisis residential/respite, intensive home-based services, emergency/crisis response and

outpatient services.

- Must be a sufficiently well-developed system of care to be able to serve as a useful example to the field and to receive national attention.

- Should have a mechanism for integrating these services, assuring and promoting matching of needs with the most appropriate service for the child and family through the use of care management, case management, and/or a teaming mechanism (this includes linkages to public systems that offer services needed by the child and family).

- Should have a mechanism for working on system issues and for the coordination of services, if the system includes several cooperating agencies.

- Should have noteworthy accomplishments in other areas, including capacity for long-term care for children and adolescents with severe emotional disorders; linkages to public sector agencies through provision of care under Medicaid or through purchase of service; special emphasis on inclusion of families in care management, care of their children, and family support; or special emphasis on cultural competence.

The request for nominations was sent to a list of over 130 key infor-

nants. The selection process yielded only 26 nominations, 3 of which were generated by one of the investigators.

Five nominees were ultimately found to have met the study criteria. Two of these were managed care organizations (U.S. Behavioral Health, Emeryville, California; Value Behavioral Health, Falls Church, Virginia), two were private for-profit service providers (Choate Health Systems, Inc., Boston, Massachusetts; InterCare Behavioral Health Services, Pittsburgh, Pennsylvania), and one was a private, nonprofit service provider (DePelchin Center, Houston, Texas). Site visit reports were generated from information gathered during the site visits (two days at each location), from study questionnaires and through other materials submitted by the sites.

#### MAJOR FINDINGS.

Despite a nationwide search, only five programs were identified that met the study criteria. An assumption can be made that, whatever progress has been made in adding system approaches to the private sector, the degree of penetration into the mainstream has been very low.

**No Private System of Care.** Regardless of the degree to which there has been change in private sector service provision, an impression emerges that true systems of care do not exist in the private sector. While many of the system of care principles have been incorporated—which is a significant achievement—the MCO and service provider sites in this study have simply created broader, more flexible and integrated *continuums* of care, rather than *systems* of care as defined by CASSP (5). For a system of care to be created—not only must the service array be expanded—but mechanisms for access to services, system-level coordination across agencies, case management and coordination at the client level, and mechanisms for financing of services must also be put in place. For the most part, as represented by the sites in this study, this has not occurred in the private sector, in which there has

been a particular failure to offer family support services or to integrate services and funding with that available through schools, child welfare, and juvenile justice systems. As such, any private sector advances in broadening the array of available services pale in comparison to the potential in a well-functioning, public system of care. In order to be fair, however, it should be recognized that most communities do not have well-developed public systems of care and, given this reality, the services offered by the study sites go well beyond those available to many public clients nationwide.

This study identified factors that suggest that a truly systematic approach will be difficult, if not impossible, to create in the private sector. While every community has the potential to create a model public system of care, there are basic limitations in private sector practice that make it difficult to develop a system of care. *The major barrier to system development is the strict adherence to the medical model within private mental health services.* This approach includes two important elements. The first is the *concept of medical necessity.* Under this precept, health care is provided under the aegis of "health insurance," and, as such, must be directed aimed at the amelioration of a specific disease entity; all other care is seen as supportive, ancillary, and someone else's responsibility. This categorization of services as either medical or supportive is extremely limiting within a system of care. It separates rather than integrates care components. In addition, the emphasis on medical necessity focuses the treatment planning process on the pathological aspects of an individual's condition which undermines the use of the strength-based approach that underlies the system of care philosophy.

The second problematic factor related to reliance on the medical model is its *focus on acute care.* Long-term, disabling conditions traditionally have been relegated to a rehabilitation status and, thus, excluded from medical attention. As a result, most chil-

CENTER FOR MENTAL HEALTH SERVICES DEVELOPS PRINCIPLES FOR SYSTEMS OF MANAGED CARE

The Substance Abuse and Mental Health Services Administration's Center for Mental Health Services (CMHS) provides national leadership for improving the quality and availability of treatment and prevention services for mental illness, particularly with respect to adults with serious mental illness and children with serious mental, emotional or behavioral disorders. CMHS staff have recognized that changes in health care financing and organization made it imperative that all parties (or stakeholders) with an interest in managed care systems work collaboratively in an effort to deliver accessible, appropriate, comprehensive, culturally competent, cost-effective services of the highest quality. Accordingly, CMHS developed a set of principles to guide stakeholders in the planning, implementation and evaluation of managed care systems. Critical stakeholders include consumers, family members, advocates, federal agencies, counties and local communities, Native American tribes, purchasers, managed care organizations and providers working within managed care systems. These principles address:

- (1) quality of care;
- (2) consumer participation and rights;
- (3) accessibility;
- (4) affordability;
- (5) linkages and integration; and
- (6) accountability.

A free two-color poster of the principles may be obtained from: National Mental Health Services Knowledge Exchange Network (KEN), P.O. Box 42490, Washington, D.C., 20015; (800) 789-2647 (voice); (301) 443-9006 (TDD). The principles may also be downloaded from the following World Wide Web site: <http://www.mentalhealth.org/>.

dren and adolescents with severe emotional disorders have most of their care provided by child welfare, juvenile justice, and special education agencies, rather than health or mental health agencies, supported by public or private health insurance. The focus on acute care has been fostered by the private sector health insurance industry, including managed mental health care, and has reinforced this

separation between mental health services and the rest of the system of care. Until a framework is developed that bridges the gap between the medical model and the concepts of rehabilitation and support, private sector clients will continue to be denied access to the system of care until the point at which they become public sector clients.

**Positive Potential of Managed Care.** While managed care has been a

much maligned health care approach, the service delivery philosophies of the managed care organizations in this study appear to be extremely compatible with the system of care philosophy. Both are concerned with offering children and adolescents care for their mental health problems using the most appropriate and least restrictive alternatives. Both understand that one of the primary vehicles that makes this possible is the availability of a full array of services. This has led to development of home-based and other non-institutional service modalities for use by both public and private populations. Although the scope of that array is seen more narrowly by most MCOs, and some services such as therapeutic foster and group home care and respite are rarely made available, the recognition of the need for a continuum of care within the managed care world has brought the public and private sectors closer together.

Both MCOs and public systems of care rely on some form of case management to coordinate and assure access to services. At the managed care sites in this study, individual clients have their course of treatment followed by a care manager, who is responsible for knowing the client's entire mental health history, accessing the specific services needed, and monitoring the effectiveness of a series of interventions. In systems of care for children and adolescents with severe emotional disorders and their families, case management has these same functions and desired outcome. There are, however, significant differences between these care coordination mechanisms. In systems of care, the case manager's role also includes team building and the provision of some direct, ongoing support to the child and family. In managed care, the care manager role additionally includes the responsibility for the authorization of specific service modalities and amounts of care, as well as for utilization review.

Even the negatively perceived cost containment emphasis inherent in managed care is not inconsistent with

## NATIONAL COALITION OF FAMILY LEADERS MEETS TO ADDRESS MANAGED CARE SERVICES FOR CHILDREN AND FAMILIES

**I**n August 1996 a national coalition of 35 family leaders from the fields of mental health, child welfare, developmental disabilities, and special health care needs gathered in Portsmouth, New Hampshire to discuss and strategize about the future of long-term supports and services for children in a managed care environment.

In the past decade, the field of long-term supports for children has witnessed the emergence of innovative and responsive approaches to supporting all children in families. These approaches to providing long-term support include: supporting children in community-based early care and educational opportunities, neighborhood schools and regular classes, and community health care services. Unfortunately, public policies and funding mechanisms too often limit the availability of these effective forms of supports and services to children and families. New health care policies such as managed care present new challenges and opportunities to offer long-term supports and services to children requiring extensive and ongoing supports.

Given the fact that states have begun to enroll children in managed care plans for long-term services and supports, family leaders felt that it was imperative to mobilize a national planning meeting. The group of 35 national family leaders and policymakers met for two days to discuss and define the values, principles, and strategies that can be used to affect national change in the field of long-term supports and services for children.

Although the participants' represented diverse backgrounds, there was unanimous agreement concerning the need to coalesce as a unified voice to affect public policy and influence statewide change. Accordingly, the coalition divided into three national work groups. One group is gathering, developing and disseminating a set of guiding principles to be used in the development of state and national reform in the area of long-term supports and services for children. These principles can be applied across any constituency group advocating for the rights of children and families in need of long-term assistance. The second group is identifying all existing family and consumer organizations who are interested in joining in the coalition for children in need of long-term supports and services. The third group is developing a model contract specifying language to assure consumer-controlled, family-centered, community-based, flexible long-term supports and services for children involved in the systems of mental health, child welfare, special health care needs and developmental disabilities. For additional information on the work of the coalition contact: The Hood Center for Family Support, Dartmouth Hitchcock Medical Center, One Medical Center Drive, Lebanon, New Hampshire 03756; (603) 650-4419 (voice); (603) 650-7722 (fax); E-mail: cindi.lapointe@dartmouth.edu



the goals of systems of care. In fact, cost savings has been one of the most important aspects of the changes following the introduction of the system of care concepts into public mental health. While this cost saving goal has not been as overtly touted as in the private sector, the perception of reduced costs following the public sector shift from institutional to community-based care has kept system of care development alive.

In both public and private settings, new ways are being developed to best take advantage of the dollars available. In this case, the technology transfer has been primarily from the private to the public sector as management strategies utilized by MCOs are now being more scrupulously applied by public systems of care. Most prominent among these are the use of outcome measures to monitor individual progress as well as system efficiency and the use of systematic processes to determine how to focus resources and maximize available funds (2). Both of these private sector strengths provide important lessons to the public sector, which has historically done poorly in the areas of outcome measurement and resource allocation and management.

The Growing Private Sector Continuum of Care. The last major finding supports the original hypothesis of the study: some private agencies are now offering private sector clients the type of alternative services seen in the public sector. The service provider sites in this study were each providing several non-hospital programmatic options for those individuals who required a service more intensive and/or supportive than outpatient therapy. These included intensive outpatient treatment, crisis stabilization, crisis respite, and in-home services. One site even offered therapeutic foster and group home care. Although most of these services were delivered within a traditional categorical program paradigm, the potential for them to be used systematically was built into them. In fact, all three study sites had developed their own managed care products and were



taking advantage of the potential to integrate their service programs. The ability of providers to offer a continuum of care that supports the positive potential of managed care is growing, and an increasing number of MCOs and other insurers are learning to utilize this capacity.

It is important to re-emphasize that, nationwide, very few provider organizations have developed the capacity for a broad continuum of care. For the most part, mental health clinics nationwide are still "stuck" in a traditional outpatient therapy mode, while hospitals are still primarily offering acute inpatient services. The valuable lesson to be gleaned from the providers in this study is that, when an array of innovative services is developed, private sector insurers will use them. As one provider said, "If you build them, they will come." In the past this adage has held true for hospital beds and it is now becoming a reality for community-based, family-centered services.

### THE SIMILARITY BETWEEN MANAGED CARE AND SYSTEM OF CARE.

An unexpected study finding was the recognition that the underlying principles of managed care are similar to and entirely compatible with those of systems of care for children and adolescents with serious emotional disorders and their families. Both sets of principles aim to offer the most appropriate level of care that an individual needs at any moment in time. In the system of care this is represented by the concept of least restrictive environment and in managed care this is represented

through levels of care guidelines.

In addition, both system of care principles and managed care principles rely on flexibility in the use of services and in finding innovative approaches. In managed care this is manifest in those instances where managed care contracts allow for an unlimited benefit as incurred by those organizations found in the study. While not as inclusive and malleable as public sector wraparound services, the unlimited and well-controlled benefits offered under some managed care plans are based on the same understanding: the correct amount of the right services leads to the most positive result while also being the most efficient.

For managed care to reach its potential, it must be funded adequately and utilize care management and service provision policies which emphasize full-service delivery. Similarly, public systems of care can only reach their potential when the efficiencies of care management and fiscal responsibility—the hallmarks of managed care—are utilized.

### CRITICAL PRACTICE ISSUES.

When a reasonable managed care product is adequately supported monetarily, its concepts are entirely compatible with the principles of public systems of care. Both managed care organizations in this study were attempting to approximate the theoretical potential of managed care. They have done this by creating an approach that focuses primarily on service delivery rather than on costs. First, they created a clinical model of care management in which licensed and experienced mental health professionals are asked to make clinical judgments within the context of high-level (often psychiatric) supervision. Secondly, they encouraged employers to purchase liberal benefit packages from them.

Each of these organizations offer an unlimited mental health benefit that is closely managed. In doing so, they recognized that the best and most efficient care is that which can be crafted to meet an individual's spe-

cific needs and is flexible enough to be modified as necessary. When controlled by a care manager who knows the facts and history of the case and the full range of service alternatives in the community, this care can be more clinically appropriate and, often, less costly.

Further, both managed care organizations acknowledged the need to view child and adolescent services as different than those provided to adults.

This has encouraged the identification of providers who can offer child-oriented services and the development of mechanisms to support them.

Finally, the leaders of the programs nominated for this study formerly worked in the public community mental health and child-welfare oriented arenas. Their approach to services focuses on the special needs of children and adolescents and an appreciation for non-institutional,

community-based services. These leaders created a full continuum of care heavily focused on hospital diversion.

## A BALANCED VIEW.

This study presents a positive view of managed behavioral health care's potential to provide systematically delivered services; however, it is important to recognize that the dream of managed care is far from reality. While there is a potential within managed care to enhance the delivery of services, much of current managed care practice focuses on cost containment and profitmaking.

Unfortunately, child-serving professionals have rarely had the opportunity to see care managed in a positive way. Rather, they experience service restrictions and demands that require them to practice in a manner contrary to their training. The increased paperwork that accompanies managed care, although necessary for the efficiency of the managed care organization, is burdensome to clinicians and agencies alike.

This is similar to the experience of many family members with children and adolescents with more severe mental health problems. They often see limits rather than better care; rigidity rather than flexibility in service allocation. When a child's care needs become intensive and long term, families are faced with being denied further services. When their mental health benefits have been exhausted, the care for their child is most often shifted to public sector agencies such as schools, child welfare and juvenile justice.

Managed care organizations take little responsibility beyond the confines of the individual's benefit package. By definition, they can only offer a partial approach to care—the acute part. While family members might initially obtain a systematic, well-designed intervention, when benefit limitations are reached, they get nothing. When there is an avenue of eligibility, their care is shifted to the public sector. While this is not unlike the rest of the health insurance

## EGG HARBOR FAMILY SUMMIT ESTABLISHES CHILDREN'S MANAGED CARE PRINCIPLES

In September 1995 about 30 parent leaders from around the United States gathered at Egg Harbor, Wisconsin to discuss health care for children with special health care needs. Based on a universal concern about the unknown effects of managed care on children, the families developed a set of family-driven standards for managed care systems treating children with special health care needs. The families identified five key principles that should guide the delivery of services to children with special health care needs in a managed care environment.

**Families are the core of any health care system.** Managed care systems should: acknowledge and support the expertise that families bring to their caretaking, decision-making and care-coordinating roles; accept and value the richly diverse traditions and languages families bring to health care settings; and respond to the needs identified by families and providers.

**Family-professional partnership.** Managed care systems should recognize that outcomes for children with special health care needs will improve when families and professionals make decisions jointly, with each party respecting the expertise, experiences, training and resources that each brings to the care of the child.

**Access.** Children with special health care needs should enjoy unconditional and equitable access to quality primary, preventive, habilitative, and specialty health care services and equipment at reasonable cost to their families.

**Flexibility.** Medical decisions and referrals should be based on the unique circumstances of the family and condition of the child.

**Comprehensive, coordinated, community-based care.** Managed care systems should assure a coordinated system of comprehensive services to children with special health care needs and their families through direct service provision within the plan and collaboration with public and private community services outside of the plan. These services should be delivered as close to the child's home as possible, and include appropriate outreach to underserved families.

In addition to the principles, the participants at the Egg Harbor meeting developed an extensive list of specific strategies for putting the principles into action. For additional information concerning the principles developed at the Egg Harbor meeting, contact any of the following: Bev Crider, Michigan Department of Health, Plaza Building, 3rd Floor, South Tower, 1200 Sixth Street, Detroit, Michigan 48226, (800) 359-3722; Josie Thomas, Institute for Family-Centered Care, 7900 Wisconsin Avenue, Suite 405, Bethesda, Maryland 20814, (301) 652-0281; or Polly Arango, Family Voices, P.O. Box 769, Algodones, New Mexico 87001, (505) 867-2368.

industry and many public mental health programs, it does not live up to the promise of managed care.

The realization of the full potential of managed care and the integration of the system of care principles into the private sector requires the following:

Employers must recognize the value of increased mental health among their employees and their family members. As long as corporate America is satisfied buying a cheap and inadequate mental health service package, there will be no room for improvement in service delivery. The process of educating employers could be facilitated if employees—the consumers of mental health care—understood the need for and demanded more appropriate services and a system of care approach for addressing more severe problems.

Managed care organizations must shift their philosophical balance from cost containment to service delivery. The companies in this study demonstrate that a "service first, cost containment second" approach is feasible, marketable and profitable. Most managed care organizations express this philosophy, but the rhetoric is hollow when they agree to contracts that do not provide adequate resources to actualize it.

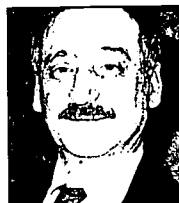
Related to the balance in service philosophy is the issue of profit. There are no standards as to the acceptable degree of profit a health care insurer or care management company should reasonably make. While some would argue that it is unconscionable to make any profit on health care, it is probably more realistic to address the limitation of profits. Regulation of profits would make reaching an appropriate balance between cost containment and service delivery easier to attain.

The full range of service modalities must be widely accepted. Many employers, managed care organizations and service providers adhere to an extremely traditional mental health service model that focuses on inpatient hospitalization and outpatient therapy, with some partial hos-

pitalization and short-term residential treatment. This study demonstrates that a broader continuum of care is not only within the bounds of good clinical practice, but also offers better and less expensive services.

An enormous amount of money and other resources must be invested to create a service system that can meet the individual needs of the entire—public and private—child and adolescent mental health consumers population. To date our society has been unwilling to make that investment. Accordingly, we have mis-spent a large percentage of our current funds on overly-expensive inpatient services. As this study demonstrates, however, when we are ready to make the necessary commitments, both the knowledge and the technology are available to create a system of care that can meet the individual needs of the whole population.

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## MARK YOUR CALENDARS

**Annual Building On Family Strengths Conference**  
May 8-10, 1997  
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### For Additional Information:

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## MANAGED BEHAVIORAL HEALTH CARE AND FAMILY INVOLVEMENT: THE ARIZONA EXPERIENCE

**B**rief History. Prior to 1988, Arizona's children and families in need of behavioral health services were faced with a practically non-existent service system. The typical service offered was out-of-home treatment. As a result of the lack of coordination and limited service availability, a coalition of families, child advocates, behavioral health professionals and others interested in making a change for the better gathered as a coalition and made recommendations to change the system. These efforts resulted in the enactment of two children's behavioral health statutes.

Arizona Revised Statute §36-3421 created the Council on Children's Behavioral Health. This 22-member council oversees the development of the children's behavioral health system and makes recommendations to the Governor and to the Arizona Legislature. The statute requires that a minimum of four members of the council shall be parents or guardians of children receiving behavioral health services. In addition to appointing parents or guardians, the Governor, Speaker of the House of Representatives and President of the Senate appoint an additional nine council members. The remaining members required by the statute include representatives from the five child-serving state agencies and a representative of the Navajo Nation.

Arizona Revised Statute §36-3431 directs the Division of Behavioral Health to develop and implement a comprehensive behavioral health service system for children. Accordingly, an intergovernmental agreement between the state child welfare, education, juvenile justice and behavioral health systems was established. This agreement provides for the development of a collaborative needs and resource assessment and the development of a funding and service delivery plan.

The Arizona Health Care Cost Containment system (AHCCCS) is

Arizona's Medicaid program and the state's health care program for persons who do not qualify for Medicaid. The AHCCCS acute care program is currently in its thirteenth year of operation. When the AHCCCS program began in 1982, from the state's perspective, it was necessary to delay the implementation of behavioral health care services until the program could stabilize: In 1990, AHCCCS began phasing-in comprehensive behavioral health services starting with Medicaid-eligible children under the age of eighteen who required residential care. Behavioral health services for Medicaid-eligible children under the age of eighteen who did not require residential care were added on April 1, 1991. The eighteen, nineteen and twenty year olds also began receiving services on this date.

The "phasing-in period" (which was more of a slam dunk) created much chaos. Providers, family members and adult consumers were completely lost. After the dust settled, we had a clearer view of the direction we needed to go in. We needed to continue to stay together and ensure that our voices were heard in planning our system of care.

Today, Arizona's Behavioral Health Department chose to divide the state into five regions. The state contracts with Regional Behavioral Health Authorities or RBHAs. These RBHAs are all non-profit and are required by contract to have family members on their boards of directors as well as on their quality assurance committees.

Local children's councils are an outgrowth of the Children's Behavioral Health Council. Parents serve on some of the local councils. Each of the five state regions has at least one local children's council. The RBHAs regularly participate in the local council meetings. Local council members come together four times each year at various locations throughout the state to receive updates on the activities of the monthly state council meet-

ings, familiarize themselves with specific local concerns, and share information concerning what is working well in various parts of the state.

**Cultural Competency.** Behavioral health needs cross all cultural and ethnic backgrounds. Yet multiple barriers exist for Native Americans seeking treatment and other assistance. Some of the concerns that have faced our nineteen Native American tribes include geographic isolation, lack of support for traditional Indian healing approaches, inadequate funding and unclear roles and responsibilities. Each tribe has representatives on the Inter-Tribal Council of Arizona. This council is very active in addressing and presenting the needs of our Indian people.

In an effort to identify strategies for addressing the challenges of Native American people with mental health needs a national conference, held in Albuquerque, New Mexico in April 1993, brought together over 250 mental health care representatives and family members. In June 1994, a follow-up conference attracted approximately 80 participants to specifically examine the needs of Arizona's Native Americans.

As a result of the follow-up conference and other cultural needs, Arizona citizens developed a cultural competency plan for the administration and delivery of behavioral health services. The steering committee included representatives from provider agencies, behavioral health planning and advisory councils, families, tribes and other state agencies. The implementation of the plan will be annually assessed at the state, regional and local provider agency levels beginning in January 1997. The Children's Behavioral Health and State Planning Councils will regularly review and make recommendations on the basis of the assessments.

**Family Involvement.** Arizona has always prided itself on its legislatively mandated family involvement in



planning and policymaking. Although I concur, in practice it has been difficult for families to travel to Phoenix for countless meetings. Further, most family members had no idea how committees operate. Although families were pleased when the state began to reimburse them for the expenses associated with their participation in meetings, reimbursement alone was simply not enough. Only a very small number of family members were involved and—of those families—few represented ethnically diverse or rural populations.

When the opportunity presented itself, I joined M.I.K.I.D. (Mentally Ill Kids in Distress), Arizona's statewide family organization for children's mental health. Subsequently, I became president of our board of directors. I was determined to seek funds for our organization to help educate family members and encourage their involvement. M.I.K.I.D. successfully negotiated a contract with the Department of Behavioral Health Services to provide education to families as well as professionals; participate on various councils, committees and task forces; develop a parent manual; pro-

vide one-to-one advocacy; and increase the number of support groups around the state. Each regional behavioral health authority contributes funds to the state that help support the provision of our services.

Although M.I.K.I.D. is funded through our state contract to provide an array of services, we continue to struggle to increase the number of family members involved in planning and policymaking. We work closely with state officials and with local providers to help us identify family members who would benefit from our services as well as to recruit them for service on Arizona's various councils and committees.

Arizona has been in the managed care business for some time and we are very proficient in our ability to "manage" costs. One of the ways in which we have contained costs is to limit the number of individuals eligible to receive publicly-funded managed care health services. The 1996 federal annual income poverty level for an individual is \$7,740.00. Arizona restricts eligibility for some of our programs to as low as \$2,863.80 in annual income (37% of the federal

poverty level). The share of federal funding we receive is also low because our state so severely restricts who can qualify for services. Medicaid recipients have priority in the service delivery system.

Although our service matrix covers a wide variety of services (including Native American traditional healers' reimbursement and wraparound flexible funding) the non-Medicaid population is not able to access all of the services. Few of our families have the time and energy to become actively involved at the policymaking level because their own family's present needs are not being met through our system. Promoting family involvement is an ongoing process which should be relentlessly encouraged—if not mandated—from the agency level to the highest state levels.

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*Teri Sanders*

## GEORGIA FAMILY ORGANIZATION PLAYS KEY ROLE IN DELIVERY OF CHILDREN'S MENTAL HEALTH SERVICES

In 1982 Jane Knitzer described federal leadership in the areas of children's mental health as the "unfilled promise." As a result, a coalition of individuals and groups advocated to Congress and funds were appropriated for a federal initiative for children with mental health disabilities. In 1984 the National Institute of Mental Health (NIMH) launched the Child and Adolescent Service System Program (CASSP). The goal of the CASSP program was to assist states and communities to develop systems of care for children and youth with several emotional disorders. Georgia was one of the first states funded by this federal initiative and, as part of the state plan, developed a core group of family members that they sent to

CASSP meetings in Washington, D.C. and to Families as Allies meetings around the state of Georgia. This group of parents, with the support of the Georgia CASSP program, formed the foundation of the Georgia Parent Support network.

The Georgia Parent Support Network, Inc., was founded in 1989 by 30 parents and professionals who shared a vision of family involvement in issues that affect children and youth with mental health disabilities. The Network has grown to over 2,500 members. The members sit on almost every policymaking board where decisions affecting children and youth with mental disabilities are made. Network activities include a quarterly newsletter, parent support groups,

two conferences a year, individual family advocacy, a toll-free 800 telephone number and, in the last year, the delivery of direct services that include respite, parent advocates, a juvenile justice safety net, and oversight monitoring and implementation of services in Fulton County. The Network continues to grow and is constantly redefining the family advocacy role to determine where families can and should be involved, to ensure that the needs of families whose children suffer from serious emotional disabilities are met.

In 1993 a number of different advocacy organizations—representing mental health, mental retardation and substance abuse—came together to develop and support legislation that

will forever change the way services in Georgia are delivered to adults and children who suffer with mental health, mental retardation and substance abuse disabilities. The Georgia Parent Support Network helped craft this legislation and was part of the advocacy effort to get it passed. Georgia's House Bill 100 divides the state into nineteen regions and created regional boards. Fifty-one percent of the board seats are reserved for consumers and their family members.

Georgia's nineteen regional boards oversee the planning, purchasing, and evaluating of all mental health, mental retardation and substance abuse services. Prior to the legislation, 92% of all services were delivered by the public system. Consumers had little choice in selecting services. Further, services were not equitably distributed throughout the state—many areas had very few services available—and there were few checks in place to measure consumer satisfaction.

House Bill 100 returned local control of services to communities. Appointments to the regional boards are recommended by the local county commissioners according to a formula that was developed to ensure that all three disabilities (i.e., mental health, mental retardation and substance abuse), children, and ethnic minorities are equitably represented. The legislation recommended several advocacy organizations to the commissioners as people to involve in the development of the boards. The Georgia Parent Support Network was one of these organizations.

House Bill 100 represents a paradigm shift in the way mental health, mental retardation and substance abuse services are delivered in Georgia. The crafting of the legislation, the oversight of the passage of the legislation and the following transition phase has been closely monitored by the "811 Commission." The state leaders serving on this commission have given hundreds of hours to ensure that the transition has been as smooth as possible. There have been countless committees and hearings throughout the state of Georgia for

the past three years to ensure that every voice is heard and validated. The topics addressed at these hearings include: (1) single point of entry into the system; (2) best practices, liability, evaluation processes, equity of services between disabilities, and ensuring a smooth transition from the former public system to the new public/private collaboration.

While the process of restructuring the entire mental health, mental retardation and substance abuse system was underway, managed care and its concomitant new challenges and opportunities arrived on the scene. Georgia decided to "carve out" these services and submitted an 1115 waiver. The Georgia Health Policy Center at Georgia State University is developing final recommendations concerning the role of managed care in the delivery of all health care services. The Behavioral Health Planning Unit, a state agency created to specifically address the needs of consumers of mental health, mental retardation and substance abuse services within managed care, is advising the Georgia Health Policy Center on these matters.

The Georgia Parent Support Network has been very active in the entire managed care process. The president, board chair, other board members, and members of the organization at large have attended most of the meetings held by the Behavioral Health Planning Unit. The state of Georgia sponsored key people from child welfare, education, mental health, juvenile justice, youth services, the Georgia Parent Support Network and the Behavioral Health Planning Unit to attend a conference on managed care in California. As managed care continues to unfold, many more families are becoming involved in the process.

The Network, in response to the political challenges of the last eighteen months, decided—in order to provide for the needs of families and children and to meet the challenges of the future—to become involved in the new public/private venture to improve and expand services to chil-

dren with emotional disabilities. To this end we developed a "safety net" that provides community stabilization and safety for adjudicated juvenile sexual offenders. If these children were not in this program they would either be in a mental health institution or incarcerated in a juvenile detention facility. This program enables them to receive out-patient treatment, live safely in their communities, attend school and church, play Little League, attend summer camp and do most of the other things children their age do.

The Network developed a respite program that has two components. The first component is crisis intervention. If a child is in danger of being removed from his or her home, the Network provides an emergency respite placement that often stabilizes the situation and diverts hospitalization. The second component is planned respite, where breaks are scheduled that allow families and children time away from each other so that crisis situations may be averted.

For the past year, the Network has provided seven parent advocates to a three county region. These advocates work with families with many different needs. Their job is to assist the family in any way y needed. Duties include attending Individualized Education Plan (IEP) meetings, helping individuals obtain Social Security benefits, attending juvenile court proceedings, and assisting individuals with their transportation, food, housing, medication utilities, support and legal assistance needs.

The Network has worked with several service areas as they implemented new services or fine tuned existing services. The services provided to these regions include technical assistance in the following areas: (1) developing and maintaining parent support activities; (2) promoting and maintaining parent involvement on local boards and committees; (3) developing child and adolescent regional services plans; (4) developing policies and procedures for new child and adolescent services; and (5)

hiring staff to work in the new programs.

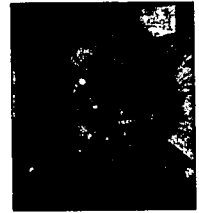
In January 1996 the Network successfully bid on and received a contract to implement, monitor and evaluate services for children and adolescents with serious emotional disabilities in Fulton County, City of Atlanta. Through a children and adolescent committee that included interagency members and community leaders, the regional board contracted for services that would comprise a community-based system of care for children with emotional disorders. A mix of public and private organizations are responsible for the delivery of services. The foundation of this service delivery system—called “Fulton’s ChAMPS”—is interagency and community collaboration. The Network works with all agencies to ensure

coordination. A parent advisory board has been formed. All children placed out-of-home and out-of-community are monitored and every effort is made to return these children to their local communities. Network representatives attend all administrative and interagency meetings. The Network was recently able to hire a parent who will meet with each family whose child is in the ChAMPS program and offer support as well as monitoring customer satisfaction. The Network administers the flexible wrap-around funds and maximizes these dollars by soliciting community contributions.

Georgia Parent Support Network members believe that tremendous strides toward family and consumer empowerment have been achieved since the first CASSP initiative. However, the needs of our families and

children are so great that what has been accomplished is only the beginning. For lasting changes to occur families and youth must be involved at every level in every system. Families and youth must serve on boards, advocate for their needs with their elected officials, offer to testify, serve as role models for other parents and not be afraid to let their voices be heard.

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Sue Smith

## MONTANA'S MANAGED CARE GOLD RUSH

Montana is once again experiencing the heady exhilaration of the Gold Rush era. One hundred years after the mining bonanza of the 1890's, we again find ourselves seeking gold—this time extracted from the bedrock of mental health care. The energy of the present is no different than that of a century ago. Those who stand to profit promise the moon—unparalleled changes in mental health services. Those whose lives will be profoundly affected are anxious to believe the promises and are also leery of the barren moonscapes hidden in the clouded words. As with the first Gold Rush, voices of reason and of caution are often drowned in the enthusiastic and unchecked energy of hope. History often repeats itself, and the specter of ghost towns—of individuals and families without services—looms in the nightmares of many in Montana.

But all is not bad dreams and spec-ters in the night. The development of a managed care system for Montanans with mental illness presents opportunities as well. Commitment to the development of community-based

services, reduced out-of-home care for children, better outcomes for families—each of these depends upon a willingness to promote system change. The key is to be thoughtful, to listen to those most affected, to monitor the impact, to celebrate what is good and to change that which causes harm.

Montana began the journey to managing health care in the Medicaid population through a series of decisions affecting the provision of physical health care. The success of these efforts to provide cost reduction and control of decisions for health care prompted examination of the runaway mental health services budget. Also, the frustration of state and local providers who coordinated mental health care prompted an “any port in a storm” mentality to shed the difficulties associated with negotiating the troubled and uncharted waters of system change.

Initially, several factors hindered the system change process. Prior to 1995, the Montana Mental Health Division was located in the Department of Corrections. The Medicaid

Division was housed within the Department of Social and Rehabilitative Services. Funding for mental health services was fractured between other departments as well. In particular, children were funded through the Department for Family Services, Department of Health and the Office of Public Instruction, as well as other agencies.

Many mental health services were contracted to regional, private, non-profit mental health centers. These centers provided priority services to adults with severely disabling mental illnesses and children with serious emotional disorders. These services were funded through mental health block grants, Medicaid, and state-funded fee-for-service agreements.

The runaway Medicaid budget raised the concern of people throughout the state. Children’s services—particularly the costs of residential care—skyrocketed. Legislation was proposed in 1993 to eliminate the “Rule of One” funding mechanism by which children were deemed eligible for inpatient and residential services based solely on their income. Advo-



cates and providers joined together to restructure the eligibility process with the promise from state mental health administrators that the savings generated would be re-routed to community-based alternatives. Two very powerful ideas germinated from these discussions: (1) pool funding for children's services (key to the managed care process three years later) and (2) the creation of Managing Resources Montana (MRM)—the first step toward managed care for kids.

MRM is a community-based system that provides care to eligible children with serious emotional disorders. The system was created through a cooperative interagency agreement between six state agencies. The MRM design included governance by regional teams composed of agency representatives, parents or parent advocates, service providers and community representatives. The plan for regional control garnered enthusiastic support, however, the state eventually pulled back and sought to centralize control.

Despite the controversy surrounding MRM, managed care for Montana's children with mental health needs is now a reality. Significant benefits resulted despite numerous flaws in the systems. Two of the regions developed community-based services, successfully limited residential care by providing home-based services, involved families in meaningful participation, and developed a regional commitment to transform the way business was conducted. With undaunted enthusiasm, one region began to initiate programs that better served the population. Money made more flexible by MRM rules was directed to a variety of services including respite, quick response case management, therapeutic aides, wraparound services, and home-based care. Other regions approached the promise of change more cautiously. Administrators, geographic considerations and services already in the region greatly affected the development of new services.

Response to MRM from parents and providers was mixed. Access to



services was significantly limited by fiscal concerns. Regional interpretations of policies caused political dissent. Families were confused and wondered to whom they should turn for information and guidance. Providers were frustrated by the lack of control in decision-making processes, and acute care facilities found the residential treatment route to discharge planning had been blocked. Perhaps most of all, both state and regional participants took umbrage concerning issues related to control and responsibility. Where new services were initiated, enthusiasm was high from both parents and providers. Case management was required for all contracts and varied from region to region in implementation and form. The first steps into the managed care environment had been taken and Montana began tottering toward a bigger goal—full scale development of a statewide mental health managed care program.

Thus the stage was set for the development of a request for proposals (RFP) from managed care organizations to manage available mental health funds to serve both adults and children. A Health Care Financing Administration 1915(b) waiver application was granted. Such a waiver allows Montana to operate its Medicaid program in a way that does not comply with all of the requirements of federal law.

The array of elements contained within Montana's RFP includes pooled state funds, capitated rates, defined access by diagnosis, community-based services, state hospital beds (adults only, but a significant factor), parent information, education

and outreach, a unique caveat for Native American involvement, school-based programming, assessment, emergency services and case management. Utilization of local expertise—including that of the family—is clearly set forth as one of the RFP's expectations. Companies' proposals must demonstrate how they will develop local partnerships. Family members and consumers fear involvement in name only.

Bids to assume responsibility for Montana Mental Health Care are being reviewed by a state-appointed evaluation committee. The committee is guided by a set number of points addressing six areas: program description, implementation, organization description, experience, resources, and commitments. Notably absent from this list is the evaluation of a transition plan that, arguably, is included within the overall program description.

Several areas of concern with the proposal have surfaced. From the children's services point of view, a major concern is the lack of protection of children's dollars within the funding mechanism. Family organizations such as Family Support Network struggle with defining a role within the service delivery system that allows it to provide non-traditional support services to parents. Medical necessity is a pivotal factor and its interpretation by the managed care organization is key to the success of the program. The lure of profit at the expense of an under-served population frightens many. Access to services by the working poor and standards to protect children from being dropped from services are vague. Perhaps most frightening of all to most informed parents and providers is the experience had by peers in other states.

All of these unresolved issues and more are the stuff of nightmares. Managed care is here to stay, but questions still remain. Has the state of Montana rushed too quickly to implement a new concept? Montana will be the first state nationally to pull all mental health dollars, block grants, state



hospital funding, community mental health monies, and all Medicaid (but not Medicaid general fund dollars) into a single contract.

Is it appropriate to push the envelope and force change? Will the first year of implementation result in chaotic or orderly service delivery? From a provider perspective, can adjustments be made to form legal provider networks within a significantly abbreviated period of time? Is there sufficient time—since the release of the request for proposals in August—to develop adequate proposals, evaluate their merits, negotiate a contract, and begin implementation prior to January 1, 1997? There are many who believe four months is simply too short a period of time to accomplish such significant tasks and to assure

quality care for Montanans with mental illnesses.

The issue of outcomes and planned, careful scrutiny of the managed care organization's service delivery system, once in place, was sadly neglected in the preparation. Outcome tools and accountability received cursory review by the advisory committee. A sub-committee submitted a single report but no further discussion occurred. Profit caps, grievance procedures, regional provider networks, parent involvement and children passed to juvenile justice to save money are concerns that nag at family members as promises pour forth from managed care organization executives and state officials.

Meaningful discussions have brought the state to the crossroads of systems change. Have the voices of

family members, consumers, parents and providers been heard and taken seriously? Many of the recommendations submitted have been ignored. Many people sought to slow down the process and to assure meaningful transition to a system that has promise. The repetition of history—rushing to mine gold—is regrettably the closest image to what is happening in the Big Sky Country.

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Barbara Sample

## PHILADELPHIA COUNTY DEVELOPS FAMILY-FRIENDLY BEHAVIORAL MANAGED CARE PLAN

In January 1997 Pennsylvania will replace fee-for-service Medicaid with managed care for both physical and behavioral health care in the southeast region of the state. During the past three years, while the State was planning for the conversion to managed care, Philadelphia worked actively with both elected and administrative state officials to assure that the conversion would allow Philadelphia's behavioral health system to flourish. Because of the positive relationships among the County Office Mental Health and the family, consumer and advocate communities, they provided leadership and support in working with all levels of state government.

In part because of the efforts of local government and family advocates, Pennsylvania chose to "carve out" behavioral health from the physical health contracts for managed care. The state offered each of the five counties in the southeast region—which includes Philadelphia—the options of creating a managed care entity for Medicaid-funded behavioral

health services, subcontracting behavioral health services to existing managed companies or allowing the state to manage the contract for behavioral health care services. Among the counties, only Philadelphia has chosen to manage Medicaid funds directly rather than working with existing managed care companies.

Philadelphia County has developed a behavioral managed care company as a component of the Department of Public Health to respond to the opportunity to manage Medicaid funds. A major impetus for the decision to create Community Behavioral Health (CBH) was to preserve, expand and improve the County's family- and consumer-guided public behavioral health system. CBH is a quasi-governmental entity. It is one of three components of the City Health Department's behavioral health system, which also includes the Office of Mental Health and the Coordinating Office of Drug and Alcohol and Alcohol Abuse Programs. All components are part of the Philadelphia Behavioral Health System (BHS), which

reports to the Health Commissioner.

Because Philadelphia's goal is to develop a behavioral health system that effectively meets the needs of children and their families, it has been essential to assure the CASSP goals and philosophy are integral to the new system. CASSP goals are being incorporated into the policy, operational and advisory structures of the new behavioral health system. The new system is using several mechanisms to assure that the development and delivery of children's behavioral health services will be guided by families to meet the needs of their children. These mechanisms include the active participation of families whose children use behavioral services on all Behavioral Health Care committees, specialized service training and supervision for staff who oversee children's services and the development of a Family Satisfaction Team to assess directly the quality of services supported by the Behavioral Health System.

The commitment to CASSP values is reflected in the composition of the

## CONSUMER PARTICIPATION AND RIGHTS

Managed care systems should:

- meaningfully involve consumers and family members in the planning, development, delivery, evaluation, research and policy formation of managed care systems including the determination of "medically necessary" services;
- respect consumer choice of services, providers and treatment and assure consumer informed voluntary consent. Individual treatment plans should be based on the preferences and needs of consumers and families with children;
- ensure that consumers receive necessary legal and ethical protections and services;
- provide education to consumers and family members on their rights and responsibilities;
- establish grievance, mediation, arbitration, and appeals procedures to resolve consumer disputes in a timely manner. Ombudsman services should be provided. Necessary services should continue pending dispute resolution;
- support consumer rights and empowerment by providing education about, and access to, local self-help groups and protection and advocacy organizations; and
- ensure that confidentiality and privacy of consumer health care information is protected at all times, particularly as electronic information systems develop and expand. Release of specific information should occur only with a signed release from either the recipient of services or their legal guardian/representative.

*Excerpted from Principles for Systems of Managed Care (1996). Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. See ordering information on page 5.*

committees that have a critical role in policy development and operations. The committees all have significant family representation and the membership of the committees is reflective of the cultural composition of the populations to be enrolled. Philadelphia's mental health service system has worked closely with families and consumers in all aspects of policy development for most of the last decade. The committees guiding the Behavioral Health System have been created to assure that the new system reflects the Health Department's commitment to consumer and family-driven service provision. Members include a wide range of stakeholders, including families, providers, advocates, consumers and representatives from several child-serving systems.

The committee structure also acknowledges the differences among systems of care for children and adults. In developing committees, it was essential to assure that the voices of children and their families were not overwhelmed by advocates for adults with behavioral health care needs. There is a Children's Services Committee composed of families (both parents and grandparents) of children with emotional disorders, families who receive services from the local Children and Youth Agency, families whose children use substance abuse services, legal advocates for children and families, and representatives from the school district, the local children and youth agency, juvenile justice, and family court and service providers. This committee has been developed to provide advice and oversight to all aspects of Philadelphia's behavioral health system for children and their families. Families of children who use behavioral health services are also represented on every other committee of the Behavioral Health System, including the Consumer and Family Task Force and the Provider Credentialing Committee.

The operational structure of the Behavioral Health System also reflects Philadelphia's commitment to children with emotional disorders and

their families. A children's behavioral health specialist will routinely report to the clinical director. The specialist will ensure that the system reflects CASSP values and is responsive to children and their families. While the specialist will work closely with both the mental health and substance abuse specialists, the children's behavioral health specialist's work will not be subsumed by their issues.

In addition, other staff will specialize in the children's behavioral health system. Respectively, member service staff who will interact with families and consumers, and service management staff who will work with providers, will specialize in either children's or adult services. We believe that this is a stronger model than using generalists who may regard children's issues as secondary to those of adults. The separation of services for children and adults acknowledges that managing the children's system requires specialized knowledge and works in partnership with other systems such as education and child welfare.

A third mechanism to assure that families have an active role in the Behavioral Health System will be through the Family Satisfaction Team—a group composed solely of families whose children use services and older adolescents who use behavioral health services. This team will be supported by the Behavioral Health System, but will be independent of other administrative or established advocacy agencies. It will be charged with working directly with families and children to monitor services and to make recommendations for improvement. The Family Satisfaction Team will visit programs to speak to children and adolescents and will solicit information on services from the families of children using behavioral health services. It is expected that the feedback of the Family Satisfaction Team will be critical to the improvement of the quality of services offered through the Behavioral Health System.

The families of children who use the Behavioral Health System will make essential contributions to its

development and operations. A successful managed care entity must use its resources wisely, investing only in services that are accessible, acceptable and effective. It is impossible to design and maintain a system that meets the needs of families and their children without close attention to their voices.

We believe that families will guide the system in offering more effective and efficient services for children. It is also quite likely that families will

identify services that are not currently available in Philadelphia's existing service system. The promise of public management of behavioral health care is the opportunity for re-investment in the system. We believe it is a more appropriate model for public service than allowing private companies to use public funds for corporate profit. We expect that the family-driven system being created in Philadelphia will, through its partnerships with families, learn to provide ser-

vices most effectively. The result will be the opportunity to re-invest savings from more efficient and effective behavioral health services. The re-investment funds will then be used to close the gaps identified by families.

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## CONSUMER INVOLVEMENT IN MANAGED CARE

Consumers, families and their advocates have been and must continue to be significantly involved in the planning, development, operation and monitoring of public mental health systems. The public responsibility for Medicaid and other state, federal or local government-funded services requires a degree of openness and information-sharing that is generally not found in the private market.

The state can and should demand significant information from managed care companies on their product, including outcomes and consumer satisfaction data. The state should require managed care companies to significantly involve enrollees and advocacy organizations in all aspects of their program. Families of children with serious emotional disorders have developed a set of principles of family involvement in the development and operation of managed care systems for children (see pages 25 and 26). These principles should guide decisions about state policy.

Various mechanisms should be considered to obtain public input at every stage of the development and implementation of managed care for people in the public mental health sector.

States should develop their plan for mental health managed care with significant and meaningful involvement of consumer, families and advocates. To accomplish this:

- Include consumers, families and advocates on the planning group (commission, task force, workgroup, etc.) that will write the draft plan.

- Provide mental health advocates the opportunity to meet with Medicaid agency or other state officials who are designing the new system and ensure that their views are considered.

- Involve the state mental health planning council (established under Public Law 99-660) in the plan's development and give it an ongoing role to review and comment on the managed care proposal and its implementation.

- Establish an advisory board of consumer/survivors, families and advocates for people with mental illness to review and comment to the Medicaid agency and the state mental health authority on the requirements and standards for managed care plans and any stipulations that will become part of the contracts with such firms. The boards should include individuals covered by the program (i.e., Medicaid recipients) and should reflect the ethnic, racial and cultural diversity of the population served by the program.

States should provide the opportunity for public input as the plan is drafted and revised. To accomplish this:

- Allow citizens to obtain a copy of the proposal and provide them an opportunity to comment on it.

- Hold (through the mental health authority, Medicaid agency and/or state legislature) well-publicized, accessible public hearings on draft proposals to develop the broad parameters for such a system prior to establishing any managed care program.

- Run public service announcements and publish a notice of intent in general circulation newspapers.

- Expect to make changes to reflect the views of the public.

Ongoing public involvement is essential. Public input cannot be limited to the planning stage. Once the managed care system is operational, mechanisms are needed to guarantee ongoing input from the public. Some ways to achieve this include formal involvement of consumers both at the state level and in managed care plans. States should:

- Set up a state-level consumer-oversight board to review implementation of state managed care. Include consumers of mental health services, family members of children with serious emotional disorders and other advocates for people with mental illness.

- Require the managed care entity to establish consumer advisory boards—including one with the specific purpose of addressing mental health issues—to provide feedback on the program and make ongoing recommendations regarding access to and quality of services.



■ Authorize the state mental health planning council to review and comment on the implementation of managed care for public-sector mental health services and give it meaningful opportunities to recommend changes in the program's management to the state Medicaid agency, mental health authority and legislature.

■ Require the state Medicaid, mental health or other appropriate agency to conduct consumer-satisfaction surveys on a regularly scheduled basis (some face-to-face), to determine if individuals are satisfied with the choices they have, their access to care, the services they receive and other aspects of the managed care program.

■ Require the managed care entity, as well, to conduct regularly scheduled consumer-satisfaction surveys, including focus groups and similar activities, to obtain substantial consumer input, and to use the results to improve its services.

Consumer rights. The responsibility of government to protect the public—in this case, the consumer of mental health services—cannot be abrogated. In designing managed care, especially in contracts with for-profit firms or agreements with private nonprofit entities, the state should require that basic consumer rights are protected, that consumers have an easy way to file grievances with the managed care organization and that a system of appeals assures speedy resolution at the state level.

The following are a list of ideal and recommended consumer rights. They are goals that advocates should urge states to adopt and implement. Some of these rights are established by law, but many are not.

■ No managed care entity may discriminate on the basis of disability, race, religion, national origin, income, gender or sexual orientation.

■ Consumers have the right to be fully involved in all treatment decisions and to participate in the development of their service plan.

■ Consumers have the right to give or withhold consent to their services plan and to amend their consent as their plan is modified.

■ Children with serious emotional disorders should have an interagency, interdisciplinary services plan developed with their family and approved by their parent or guardian.

■ Treatment plans must respect the individual consumer's choice of service and service setting.

■ Consumers have the right to refuse any treatment they do not feel is appropriate and may not be disenrolled because they have refused treatment.

■ Consumers may not be denied services that are appropriate to their needs because of their decision not to accept other services.

■ Managed care entities must ensure confidentiality of records, guarantee consumers full access to their own records and protect individual privacy.

■ Consumers have the right to establish psychiatric advance directives or durable powers of attorney specifying how they wish to be treated in an emergency or if they are incapacitated. The managed care entity should be required to educate its providers on the use of advance directives.

■ Consumers have the right to appeal decisions about their treatment when they disagree. \*\* The managed care entity must have an effective, expeditious, accessible, fair and uniform grievance procedure to allow consumers to appeal decisions about care they receive or services they are denied.

■ Consumers have the right not to be disenrolled from the plan without just cause.

In the end, there will be many variations on managed care in state systems. The most successful will be in states where policymakers and advocates do not automatically resist new concepts and ways of doing business, but at the same time remain true to their principles and protect the rights and needs of consumers as the state implements reform.

Excerpted, with permission, from *Managing Managed Care for Publicly Financed Mental Health Services* (November 1995), Judge David L. Bazelon Center for Mental Health Law. Ordering information is provided on page 32.



President Clinton

## PRESIDENT CLINTON ESTABLISHES MANAGED CARE COMMISSION

On September 5, 1996 President Clinton signed an executive order creating an Advisory Commission on Consumer Protection and Quality in the Health Care Industry. The Commission's purpose is to review changes occurring in the health care system and, where appropriate, make recommendations on how best to promote and assure consumer protection and health care quality. The Advisory Commission will be appointed by the President and will include no more than 20 representatives from: health care professions, institutional health care providers, health care purchasers, state government, consumers and experts in health care quality, financing and administration. The Commission will study: (1) consumer protection; (2) changing quality; and (3) availability of treatment and services in a rapidly changing health care system. The Advisory Commission will submit a preliminary report to the President by September 30, 1997 and a final report 18 months from the date of its first meeting.



## ENDING DISCRIMINATION IN HEALTH INSURANCE THROUGH FEDERAL LAW: A CHILDREN'S MENTAL HEALTH PERSPECTIVE

*The Washington Post, Friday, September 6, 1996. Last night, senators rebuffed in a previous attempt to improve insurance coverage for the mentally ill succeeded in passing a more modest proposal to reduce the gap with physical health insurance. The measure, offered by Sens. Pete V. Domenici (R-N.M.) and Paul D. Wellstone (D-Minn.)... [was] approved by 82 to 15... [and] was attached as an amendment to a fiscal 1997 spending bill (page A18).*

*The Washington Post, Thursday, September 12, 1996. ...the House voted 392 to 17 to go along with initiatives, approved last week by the Senate....instruct[ing] its negotiators to accept the Senate Proposals as part of a spending bill....While the instructions are not binding on the negotiators, the size of the vote...increased prospects for approval.... (page A6).*

"This is an incredible victory," I said to *New York Times* reporter Robert Pear, who used that quote to conclude his September 19th article announcing the survival of parity. The Domenici-Wellstone Mental Health Parity Amendment to the Veteran's Administration and Department of Housing and Urban Development appropriations bill was approved by the House and Senate Conference Committee, soared through Congress and went forward to the President's desk. The President's signature on September 26th turned the bill into law, a hope into policy.

The implications of passing this bill go far beyond its actual provisions, although those are a significant improvement over current practices. This version of Domenici-Wellstone requires that the aggregate annual and lifetime benefit limits in health insurance plans be the same for mental and

physical health care. These requirements will take effect on January 1, 1998, and will apply to companies that have more than fifty employees.

After a long summer of struggle, Senators Domenici and Wellstone brought the issue of mental health parity back before Congress as an amendment to an important appropriations bill. Their earlier and more comprehensive parity amendment, attached to the Kassebaum-Kennedy Health Insurance Portability and Accountability Act of 1996 was defeated by heavy opposition from business and health insurance interests. As the current, compromise version of Domenici-Wellstone moved forward President Clinton (in a letter to the House Speaker) urged its passage, writing that "People with mental illness have faced discrimination in health insurance coverage for far too long; it is time that we take steps to end this inequity."

The National Mental Health Association (NMHA) applauds the President's stand. With the President's signature, discriminatory lifetime aggregate limits and annual caps on mental health care in private health insurance contracts will be prohibited by law. Although this is a far cry from complete parity, it is a significant step forward and a cause for celebration. These incremental gains move us in the right direction, toward economic common sense for the nation and fairness for the millions of children, adults, and families whose well-being and productivity are dependent on their ability to receive appropriate mental health treatment and services.

This article looks at two dimensions of health insurance parity (parity with physical health benefits and parity as an inclusive concept that applies to a broad range of mental health problems). Both context and

values are addressed as the stage is set for reviewing the struggle over the Domenici-Wellstone Parity Amendment to the Health Insurance Portability and Accountability Act. That struggle was a clear illustration of how difficult it is to achieve justice and equality for mental health consumers and their families.

Although parity advocates were unable to influence the final configuration of the Kassebaum-Kennedy Act, their work was not in vain. Advocates showed the nation and its legislators that there is a large and solid core of citizens who are willing to come forward in support of parity. Senators Domenici and Wellstone persevered and the children, adults, and families who were losers in the early battle will be winners at the end of the war. Advocates are challenged to continue their work so that more comprehensive legislation in the future can be built around the achievements of today.

### CONTEXT AND VALUES.

Millions of Americans have gone without adequate or appropriate health insurance coverage for many years. Some have had no insurance at all, perhaps because they are not in the work force or because their children have pre-existing conditions that bar them from joining an employer's health plan. Other people have had insurance that does not cover treatment for pre-existing illness, or that locks them into a job for fear of losing coverage, or that covers them when they are well but drops them when they become ill.

Historically, coverage for treatment of mental disorders has offered even less. Many insurance plans have provided no coverage at all unless required to do so by contract or by law. Those benefits packages

that do cover mental conditions often set arbitrary limits on the number of covered treatments or on the dollars available per year or per lifetime. Furthermore, even these limited benefits may be denied in the absence of one of a very few psychiatric diagnoses. This is a common and short-sighted exclusionary mechanism that allows insurance companies to avoid paying for services for children whose emotional disorders do not fall within "acceptable" diagnostic parameters. It has also proved to be a major access barrier for people whose ethnic or cultural backgrounds lead them to express emotional pain in ways that differ from those recognized by mainstream diagnosticians.

The National Mental Health Association (NMHA), as an advocacy organization, has taken a strong stand in favor of parity. Our position reflects a firm belief that private health insurance as currently constituted discriminates against and victimizes some of America's most vulnerable citizens. We have concluded that:

- It is unjust and poor public policy to allow discriminatory limits on health care benefits, discriminatory co-payments, or discriminatory annual and lifetime caps targeting mental health services for children and adults with mental health needs. No group of American children or adults should face discrimination in health insurance.

- All American workers and their families have a right to accessible and quality mental health benefits set at the same level as physical health benefits in insurance plans.

- Clinical necessity rather than specific diagnosis should determine access to mental health benefits. Parity provisions that are limited to specific disorders discriminate against countless people, especially children, who have very serious mental health treatment needs.

Some of our most basic values

support this position. The NMHA has long held that: (1) Justice demands that everyone, regardless of disability, has the rights and responsibilities of full participation in society; (2) Mental health is essential to the development and realization of every person's full potential; (3) Mental health treatment should not have more limits on access and reimbursements than other illnesses; (4) Children with or at risk of serious emotional disorders and their families must have access to high quality, community-based, integrated systems of care; (5) All people should have access to a full array of high quality, community-based, integrated mental health services, regardless of ability to pay; (6) The promotion of mental health and the prevention of mental disorders is the responsibility of every person and social institution in the community; and (7) NMHA values inclusiveness and sees broad-based citizen participation as essential to community mental health.

NMHA is not alone in its support of parity or in its broad definition of mental health needs that should be addressed comprehensively under health insurance policies. The Bazelon Center for Mental Health Law, Federation of Families for Children's Mental Health, American Psychological Association, National Community Mental Health Care Council and American Psychiatric Association and others share our vision. These groups are unambiguous in their support of the principle that no group of people needing mental health services should be discriminated against in health insurance.

NMHA was founded by Clifford Beers, a man who spent time in the back wards of state mental institutions in the early 1900's. We believe strongly that the needs of people with serious mental illnesses should never be put on the back burner by policymakers or health care providers. We will not minimize the needs and concerns of children and families whose needs are

great although they may not carry a diagnosis that is identified with a disease of the brain. Primary consumers and their families must all be afforded the assistance they need and all persons must be treated with dignity and respect.

### THE HEALTH INSURANCE REFORM ACT.

On August 24, 1996 President Clinton signed the Health Portability and Accountability Act of 1996 into law. By then, all references to mental health "parity" had been dropped from the bill. Earlier this summer, we at the National Mental Health Association and many of our colleagues in advocacy in Washington, D.C. had thought that there was a real chance to end health insurance discrimination against children and adults with mental disorders. Under the passionate and bipartisan leadership of Senators Pete Domenici (R-NM) and Paul Wellstone (D-MN), the Senate had passed the "Domenici-Wellstone Parity Amendment" to the larger "Kassebaum-Kennedy" bill. The April 17 vote was 68 to 32 for parity. Mental health advocates for children and adults alike were thrilled, and they responded to the victory with a massive surge of activity. Determined to build on the momentum of this win, they lobbied for passage in the House and they pushed the media to keep the issue of parity before the public.

Unfortunately, other forces were also at work. Between that historic April evening and July 30, when the House and Senate conferees agreed to drop even an already compromised version of "parity" from the Kassebaum-Kennedy bill, some of the most powerful and well-financed business and manufacturing political forces in this country fought hard and openly against mental health parity. Among them were the U.S. Chamber of Commerce, the National Association of Manufacturers, the National Federa-

tion of Independent Businesses and the ERISA Industry Committee.

**Background.** All of us can relate some horror stories about health insurance, even if we do not speak about the discriminatory practices that affect people whose treatment needs relate to mental disorders rather than physical ones. The Health Insurance Reform Act, sponsored by Senators Nancy Kassebaum (R-KS) and Edward Kennedy (D-MA), presented an opportunity to craft a mental health parity amendment that would prohibit discriminatory cost control practices in private health insurance plans. Senators Domenici and Wellstone, whose families include members with severe mental illness, decided to craft that amendment. Both know firsthand what discrimination and stigma can do to individuals and families who must fight for adequate treatment and social services in America's two-tiered health care system.

Domenici and Wellstone were joined by many of their Senate colleagues, notably Senators Kent Conrad (D-ND) and Alan Simpson (R-WY), in promoting passage of the amendment. Representative Marge Roukema (R-NJ) was a strong supporter in the House of Representatives.

Within the Executive Branch, Tipper Gore continued in her leadership role as the Administration's tenacious mental health advocate. She focused great energy on the parity amendment, writing opinion articles and giving television interviews to the national media.

**Assessment.** The battle for parity during the summer of 1996 can be viewed as having had several fronts. One was the struggle with large American business interests that were resistant to any change at all. This struggle was partially successful in that there has been some movement towards fairness in health insurance coverage.

The Health Insurance Reform Act provides some relief for many Americans, including those who struggle with mental disorders. The legislation as finally passed bans insurance companies from excluding people from coverage because of pre-existing conditions. These exclusion practices have been a huge obstacle for many families with children who have serious emotional disorders and need extensive treatment and support. The bill also provides for insurance portability, thus ending "job lock" for many privately insured health care consumers.

A second front was the struggle to keep legislative language in the parity amendment itself inclusive enough to remain relevant for millions of children with intensive mental health needs and their families. There was always a possibility that parity would be extended only to people with certain severe disorders or diagnoses. Such a limitation would have effectively denied treatment access to large numbers of children and families needing intensive services. In the end, the parity amendment retained more inclusive language.

**Arguments For and Against Passage.** To me personally, the most compelling argument for passage was the simple issue of fairness, the case for social justice. In our society, children and adults with mental disorders suffer from stigma as well as from the symptoms of their illnesses, making them easy targets for discriminatory health insurance practices. Insurers may have found they could get away with denying benefits to this hidden and vulnerable population, but such practices are immoral and unjust.

There are, of course, also social and economic benefits to be gained as a result of insurance parity. We know far more than we once did about how to help children and adults with mental disorders, and how to assist their families.

In the case of children with severe emotional disorders, we know that integrated systems of care and flex-

ible wraparound services can save lives and money. Culturally appropriate services that respect family values and community strengths can yield large savings over the course of a lifetime. In the case of adults, we know that employers who offer comprehensive mental health benefits find that employee productivity increases, health improves, and health care costs may be reduced. When people are denied mental health coverage under private insurance, their treatment needs do not vanish. The costs are merely shifted onto the very strained and often fragmented public sector systems.

Arguments against passage of the parity amendments came from powerful lobbying interests. Opponents of the Domenici-Wellstone Amendment raised two major arguments which are certain to rise again.

**The role of government.** Business interests argued that requiring mental health parity would constitute a federal "mandate" and therefore would be an inappropriate intrusion by government into the private health insurance marketplace. This has been a popular argument among legislators in recent years. A parity law is a mandate, as are the laws that mandate fairness in hiring practices related to people with disabilities. Many people would argue that the concepts of fairness and justice need to be kept alive and well in American public policy, and few people actually wish to see protective laws eliminated.

**The cost of parity.** Business interests argued that providing equal access to physical and mental health services would increase the cost of health insurance for everyone and would leave fewer people with insurance coverage. Citing data from an actuarial study commissioned by the Association of Private Pension and Welfare Plans, the business lobby's position was that employers could not afford to pay for better



benefits and consumers would have to pay larger premiums with passage of federal parity legislation.

Again, this is a popular argument, but the opposition to parity exaggerated the cost issue. Any cost increase will be but a small fraction of current premiums, and insurance allows costs to be spread over large groups of people, limiting the effect on any one individual or group. The September 6th *Washington Post* story quoted above indicates that costs associated with passage of the current Domenici-Wellstone Amendment are very low. The Congressional Budget Office has estimated that private health insurance premiums will increase by 0.4 percent; employer-paid premiums will increase by 0.16 percent. That works out to about sixty cents per month—a very minor sum. It is right; it is reasonable; and it is also inexpensive to extend mental health services to those children and adults who need them.

### MOVING ON: A CHALLENGE AND AN OPPORTUNITY.

Whenever health care policy is debated at any level of government or in private industry, surely it will include attention to the needs of Americans with mental disorders. Some states already have moved to achieve parity for their citizens. In Maryland and Minnesota, for example, inclusive parity legislation has been passed that allows for coverage based on individual service needs. These states have the potential to greatly increase access of children and adolescents in insured families to affordable mental health services. The advantages of such a public policy approach are explained by Linda Raines, executive director of the Mental Health Association of Maryland: "What broad-based parity did for children and families in Maryland was to provide increased opportunities for early intervention, instead

*of waiting for emotional disorders to become severe. The law is a step to increasing the availability of treatment to children and adolescents whose problems may well become more severe and expensive to treat over time. Maryland's inclusive parity law can bring expanded access and timely care to children and families with a variety of mental health needs."*

In several other states, parity legislation has been passed, but it is less useful since it only targets specific severe and persistent illnesses. As a rule, such laws do not produce fair coverage for children with intensive mental health treatment needs and for their families.

At the federal level, Senators Domenici and Wellstone have continued to focus Congressional attention toward health insurance and coverage for mental health services. The new amendment is a modification of the original Domenici-Wellstone amendment and is a less comprehensive approach to parity, but the Senators are powerful and committed advocates who are leading us toward victory in a hostile environment. In an era of "incrementalism" we can hope to celebrate important steps forward toward fairness and economic sense.

The fight for parity is really just the start of the battle. This is especially the case in the arena of mental health services for children and families. Barbara Huff, executive director of the Federation of Families for Children's Mental Health, expresses it well: "*The long haul fight will be to educate managed behavioral health care providers about the technology of systems of care, the effectiveness of family-centered treatment, and the cost savings that result when wraparound services are delivered to families that respect their natural strengths and values. Parity without the development, and then accessibility, of comprehensive children's mental health services in communi-*

*ties will be an empty promise for many children and families with the most intensive needs."*

There is a great deal to do and we are challenged to move ahead in a unified manner. When we help the child, we may produce a healthier adult. When we help a family, we may reap great societal benefits. When we base treatment on individual needs, we may find that an improved quality of life is accompanied by a decreased drain on community resources. Parity makes sense from every point of view—not least because it meets the chief criterion articulated by the National Mental Health Association—that of social justice.

With the President's signature, the sanction of law has been brought to the concept of parity. Something that is right and just and good is being entered into the law of the land. A discriminatory practice will be ended and it will be harder for insurance companies to justify the continuation of other unjust practices.

The struggle for complete parity must continue, but advocates have every reason to pause to reflect on their achievements. We have good reason to celebrate this incredible, hard-won victory.

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Michael Faenza

**Author's Note:** Special thanks to Beth Steel for her very skillful editing of this article and to Al Guida, NMHA Vice President of Government Affairs, for his tireless advocacy for children's mental health needs on Capitol Hill.



### REMARKS BY THE PRESIDENT WHITE HOUSE ROSE GARDEN SIGNING CEREMONY

September 26, 1996

**THE PRESIDENT:** This bill requires insurance companies to set the same annual and lifetime coverage limits for mental illness that now apply to physical illness. No more double standards; it's time that law and insurance practices caught up with science. I am convinced that the more we deal with this issue; the more we will come to see all kinds of medical problems as part of a seamless web, not easily divisible into mental and physical categories. The more we learn, the more we will know that.

Today, we try to bring our institutional response to those challenges up to what we now know and what we also know is morally right. I want to thank Tipper Gore for her passionate, persistent, unrelenting advocacy of this position to the President and others. *(Laughter and applause.)* When I walked up here—you know, there's always a marked contrast when you see someone happy and you see someone sad. I know no one in whom the contrast is more marked. I would do anything to see Tipper Gore as happy as she was today. *(Laughter.)* She has fought for all of you who believe in this position. *(Applause.)*

I would also like to say a very personal word of thanks for the quiet and courageous dignity with which Senator Domenici and Senator Wellstone have brought to bear their own life's experience on this great endeavor. They have made a profound impact on me and on their colleagues and on our country at some considerable effort to themselves, and I thank them very much for it. Thank you. *(Applause.)*

*Editor's Note: Excerpted from President Clinton's remarks on signing the VA-HUD Appropriations Bill (within which the mental health parity bill was incorporated).*



### MENTAL HEALTH PARITY: U.S. SENATE SPEECHES



Sen. Domenici

[O]nly two percent of Americans with mental illness are covered with the same degree of coverage as if they got tuberculosis or cancer instead of manic-depression or schizophrenia. You can walk down any street in urban America and you will find them. It is time to give these people access to care they need, and as you see them in urban America sleeping on grates and other things, you should realize that they probably started out as won-

derful teenage children in some beautiful family. And when the costs got prohibitive and the behavior uncontrollable, they are abandoned. In fact, you find more of them in jails than in the institutions which we ought to have to help them. Most studies reveal that most of the severely mentally ill are in prisons or county or city jails because of misbehavior than in [treatment] places. Part of that is because resources are not applied, and part of the reason resources are not applied is because the insurance companies...say, "How do we make money?" So, if we lessen the coverage for mental health we get a better bargain for people who want cover-

age for the other things." But I am submitting that sooner or later we have to say to them that you all have to cover them. If you are covering physical illness and they get 6 months of hospitalization, you have to do the same for mentally ill people.

—Senator Pete Domenici  
(R-NM). *[excerpted]*

Our amendment would require health plans to provide parity in their coverage of physical and mental health. Plans would be prohibited from requiring copays, or deductibles, for mental health benefits, or establishing lifetime limits

## FEDERAL MENTAL HEALTH PARITY LAW



Sen. Wellstone

for mental health benefits, or establishing visit limitations for mental health services unless the same restrictions apply to other health services.

Mr. President and colleagues, there are several arguments for requiring parity for mental health services. First, we now have cost-effective treatments for mental illnesses and high rates of success are being achieved across the spectrum of diagnosis. For example, 80 percent of individuals with depression respond to treatment. Second of all, mental illness results in physical illness, inability to work, impaired relationships and sometimes crime and homelessness.

Would it not be better to end the discrimination and have less of the homelessness? Would it not be better to end the discrimination and enable people to work and be productive citizens? And finally, Mr. President, mental health services are already part of health delivery in the United States.

Let us have no doubt about it, this amendment leaves all decisions about the delivery of services to the private marketplace. The amendment does not require the provision of mental health services to employees specify what care should be provided, interfere with the discretion of employers and health plans to negotiate reimbursement rates as they see fit, or mandate the use of any particular kind of delivery of needed care.

What this amendment calls for is just parity. Mental illness has touched many of our families and many of our friends. It is for this reason and many others that it is not a partisan issue. Mental illness is a problem affecting all sectors of American society. It shows up in both the rural and urban areas. It

affects men and women, teenagers and the elderly, every ethnic group and people in every tax bracket. It can be effectively treated just like heart disease or diabetes. Treatment not only saves lives but it also saves dollars. That is why this amendment is so important.

Colleagues, please support us. Please end the discrimination. That is what this amendment is all about. I do not usually do this on the floor of the Senate, but I would like to dedicate my remarks to my brother who has struggled with mental illness almost his whole life. He is doing great now.

I yield the floor.

—Senator Paul Wellstone  
(D-MN). [excerpted]



Sen. Simpson

Let me just tell you that about 4 years ago a most beautiful girl in our family, the niece of my wife—my wife's twin sister's daughter, whom we

had watched grow and mature from her birth—left our midst. She was a dancer; she was an artist; she was a poet; she was a guitarist; she was a singer; she was the rainbow of life.

We did not get or understand the signals in time, and the signals were very clear as we all look back now out of sheer guilt and anguish. She was tough minded, independent, loving, strong and forceful. She would come into your kitchen and just cook up a batch and leave the stuff in the sink and family would say, "Why doesn't Susan clean up afterwards?" And then, "Why doesn't Susan work? How old will she be before she ever works?"

She began to withdraw and then she went into some religious and almost cultish activities and she had a child. And that is a beautiful child. I know that child. That is the won-

derful part of it now because Susan is gone. And after years of reaching out to us in her way and us not hearing and us not knowing, she one day decisively purchased a pistol and a few hours later purchased the ammunition and went to an isolated field, removed her shoes, sat in a crouched position in Bowling Green, Kentucky and blew her chest away.

That is what sometimes happens to these people, and we think, "Well, but they should have tried to do something for themselves."

We thought we were doing something for her. We though she was finally doing it for herself. She was taking medication, and it was working. But then something, something unknown, entered her mind and her life and she decided not to take the medication—knowing what would happen if she did not—and then her tragic plan of ultimate rejection came to pass.

[T]here is not a soul in this Chamber that has not been grievously affected in some way by these things. It is time for healing. It is time for understanding more than anything. It is time to minister. It is time to love and to be compassionate and time to learn so much more about these tragic things. For these are the people who you know and see every day, and they are making it, and they never did before, but they are now. If we can put this in this bill in this way with this language, I think it would be a tremendous benefit to them—and they are our first charge—and to the rest of us in society.

I thank the Chair.

—Senator Alan Simpson  
(R-WY). [excerpted]

# PRINCIPLES OF FAMILY INVOLVEMENT IN THE DEVELOPMENT AND OPERATION OF MANAGED HEALTH AND MENTAL HEALTH CARE SYSTEMS FOR CHILDREN AND YOUTH

Federation of Families for Children's Mental Health, Adopted July 1995

*These principles were developed through an interactive process that involved families from a wide diversity of communities representing the spectrum of families raising children with mental health needs, emotional or behavioral problems or mental disorders. These principles represent a consensus. Individual communities may have additional concerns and the realization of these principles will necessarily be adapted to local conditions.*

**P**olicy Issues. Family members must be part of the decision-making team responsible for managed-care system development. This applies to both the public and private sectors. The base of parent advocacy needs to be broadened to ensure both depth and diversity of perspectives in planning, policy development, implementation, and evaluation of managed care systems. Families reflecting the full economic, cultural, linguistic, and racial diversity *who are or will be receiving managed care services* must be included in development of the systems.

State agencies must be aggressive in ensuring managed care systems involve families in an ongoing way. Systems must develop services for the benefit of children and families. The managed care system must include health care professionals who have specialized knowledge and skills to treat the many faces of children with mental health needs. Family members must have appropriate representation on advisory boards and other groups that have the power to influence the managed care system. Concepts and principles of family involvement need to be institutionalized throughout the managed care system.

Managed care systems must be consistent with the principles of the system of care. This includes: (1) preserving the benefits of interagency collaboration; (2) involvement of family members in decision-making about the design, delivery, and evaluation of services; (3) supporting a full

continuum of care; and (4) providing individualized services tailored to the specific needs of each child and family (including holistic and alternative health care needs justified by medical necessity or personal religious beliefs).

Families need to be involved in the evaluation and assessment of the success of managed care systems. We must be sure that presenting problems are evaluated and stabilized so that our children can benefit from behavioral health care. Family members must be members of quality management teams and included in the process of determining outcome measures and data collection systems. Family members must be included in establishing "best practices" based on their experiences with the system of care.

Family representatives need to be included on the planning teams for all conferences, training and technical assistance concerning managed care.

**Services-Related Concerns.** Families must receive the information and training to be empowered to advocate for themselves. This includes: (1) information about managed care principles, practices, and systems design; (2) strategies for family involvement; and (3) education in the importance of and opportunities for influencing systems change. Efforts must be made to provide effective outreach to youth and their families in inner city and rural communities in order for them to have equal op-

portunity to access information and training.

Families must have a definitive role in the development of their child's care plan and service needs. The "gatekeeping" function of the managed care system must take into consideration and not compromise the role of the family as decision-maker for the child. For example, how utilization review of hospitalizations or outpatient treatment is handled affects the family's capacity to protect their child's best interest. The managed care system must have flexible time frames for services. "One size fits all" does not work.

The providers in the managed care system must be prepared to allow families to participate at whatever level they feel comfortable. Front line workers must be well-trained in meeting family needs and responsiveness to families has to be infused into the organizational culture. Service coordinators (case managers) need to receive in-service training from family members concerning wraparound and other appropriate services to support families. Service coordinators (case managers) need to pay particular attention to the voices of youth during in-service training.

Managed care systems must support the principles of wraparound (including "zero reject" and family-centered care) and cover the non-traditional services designed and delivered through this approach. Managed care systems must ensure that a full array of community-based

child and family support service options is developed before limitations on hospitalization and residential care are imposed or when capitation controls resources for mental health care. Continuation of relationships family members have developed with mental health providers must be protected as managed care is introduced to replace current fee-for-service systems.

Managed care systems (both public and private) must have a comprehensive and easy to use appeals process for families to access when they disagree with the service plan or other decisions made by the managed care organization.

**Financial Considerations.** There needs to be money set aside by the managed care system to support and train family organizations as consumer-based entities that have a key role in monitoring the managed care system, as well as to be involved in

complaint review and policy development. These conditions need to be in the requests for applications put out by the mental health authorities. Family organizations should receive funds from the managed care system to support advocacy for children with mental health needs, train providers, and help families take responsibility for tracking down services and utilizing the system effectively.

Regardless of whether the managed care organization is a public or private entity, any cost savings should be reinvested in children's mental health services or the system of care.

Managed care systems need to ensure families are not bearing the financial risk.

Managed care systems must cover early intervention services and other services designed to prevent escalation of mental health problems.

Managed care systems must estab-

lish and maintain mechanisms for ensuring flexible funds are available to support crisis intervention, respite care, wraparound and other and non-traditional services designs and delivery strategies.

Resources must be provided to break down barriers to participation of families who lack ample financial resources. Common barriers that families face include: lack of funds, credit cards or cash on hand; lack of transportation, child care and appropriate clothing.

For additional information on the process through which these principles were developed, or for information about the Federation please contact: Federation of Families for Children's Mental Health, 1021 Prince Street, Alexandria, Virginia 22314-2971; voice: (703) 684-7710; fax: (703) 836-1040.

## OPERATIONALIZING CULTURAL COMPETENCY IN A MANAGED CARE ENVIRONMENT

**C**ultural competence" may be defined as the state of being capable of functioning in the context of cultural difference. Cross has described cultural competence as a set of congruent practice skills, attitudes, policies and structures that come together and thereby enable professionals, an agency or a larger system to work effectively in cross-cultural situations (Cross, 1988). Managed care organizations have an obligation to systematically express inclusiveness of the culturally diverse populations within their respective service areas. Health care organizations must expect that every aspect of the organization has the capacity to deliver high quality services to all consumers. Services must be respectful and responsive to consumers' cultural values and language needs. All consumers are entitled to receive culturally proficient mental health services. It is our ethical, moral and professional responsibility to ensure that all mental health consumers have access to clinically,

culturally and linguistically proficient services.

The development of a culturally proficient system of care requires acting in accordance with the following fundamental principle: An agency or organization must systematically express inclusiveness of the culturally diverse populations to be served. The organization's staff must expect that every aspect of the organization has the capacity to delivery high quality services to all consumers. The message of inclusiveness must come from the top of the organization on down. It cannot be left to the individual staff member. If the consumer perceives that the organization's commitment to inclusiveness extends throughout the organization they will, of course, give the organization their business. If, on the other hand, the clinician steps out into the hall and calls the building's janitor in to translate for the client, the client will readily perceive that the organization does not have a commitment to inclusiveness—and these cli-

ents will vote with their feet.

The acquisition of cultural competence is a developmental process. Individuals must first look within and develop an understanding of their own cultural influences. Thereafter they can begin to pursue professional growth, skills and knowledge which they can then incorporate into their work. The focus is on developing skills to assess clients, from a strengths-based perspective, within the context of the client's culture, family and community.

Examples of the strengths perspective include: (1) viewing the family as partners in the treatment process; (2) addressing the value of spirituality; (3) multi-dimensional assessments; (4) using language that is familiar to consumers; and (5) familiarity with how communities of color understand and use health care. Further, the strengths-based perspective acknowledges differences in health-seeking behaviors and may de-emphasize Western medical models.



## CORE CULTURAL COMPETENCIES NEEDED BY BEHAVIORAL HEALTH ORGANIZATIONS.

Organizations must develop reputations that they are inclusive and inviting of culturally diverse populations. They must have staff and services that distinguish them from their competitors. Staff may assume that—since their organization's name is well-known—as soon as they open their doors, culturally diverse clientele will come in droves. In fact, however, consumers will likely have decided which organization is responsive long before they open their doors. If the organization has no history of advancing the quality of life in the community through local churches and schools, culturally diverse peoples are unlikely to use the organization's services. The agency must earn the respect of the community. This respect translates into reciprocity: "You give, we give."

Providers can position themselves in the marketplace by familiarizing themselves with local census information about population profiles by age, ethnicity, gender and census tracts.

Behavioral health organizations should develop targeted strategic plans for service in specific regions. Moreover, it is important to give particular services the flexibility to shape themselves to meet the needs of the targeted communities.

Flexible criteria for accessing services will ensure that the organization can accommodate the different ways cultures express mental health and health needs. Truly accessible system entry points will have staff with clinical, cultural, and language competency skills that are reflective of the region's population.

The organization's policies and practices should enable staff to truly put the consumer first. Staff must be allowed to do things slightly differently than the norm to really reach consumers. For example, a consumer comes in and seeks assistance concerning a personal crisis. The staffer successfully helps resolve the crisis. Upon returning six months later con-

cerning another matter, the client expects to see the same individual with whom trust has already been established. The system should be flexible enough to accommodate the consumer's desire to see the same staff person.

Management information systems should track clients throughout organizations by ethnicity, language, diagnosis, age and by treatment modality. This will give management a tool to assess the organization's effectiveness in treating clients in the most effective and least costly level of care.

## ACQUIRING CORE CULTURAL COMPETENCIES.

Assess the organization's strengths and weaknesses:

- Do staffing patterns reflect the most common languages needed in the regions served at all levels of the organization (clerical, clinical, case management, supervisors, management)?

- Do staff possess the skills and licensure required for compliance with specific state or federal requirements?

- Are the organization's service modalities culturally acceptable for a consumer-driven system?

- How user friendly is the organization from various access points (i.e., inpatient, emergency, residential, outpatient)? Do clients who are not fluent in English get the same opportunity for quality treatment? Do non-English-speaking clients access the organization at the least restrictive level of care?

Managed care providers typically promote a centralized point of access to their systems. Such an approach effectively denies access to many potential consumers. If one's community is the barrio, and the point of entry is ten miles away, the health care organization is wholly inaccessible. Access points should be decentralized and truly in the local community.

## BUILDING CORE CULTURAL COMPETENCIES.

In order to build the needed competencies within the organization, assess current staff with respect to their cross-cultural skills, language

fluency, credentials, and knowledge base of targeted ethnic communities. If there is a knowledge base to work from, invest in training in cross-cultural, community-based non-traditional modalities across disciplines and programs. Invite consumer and stakeholder feedback in planning processes and develop consumer-based outcome measures.

## BUYING AND SHARING CORE COMPETENCIES.

If cross-cultural and language skills are not available within the organization, purchase the necessary competencies by re-writing job descriptions to test for the clinical and community-based knowledge required to perform the needed services. Invest in ongoing staff development of existing and new staff to maintain the skill levels needed. Maintain a multidisciplinary-culturally diverse focus and cross-train staff where possible. Contract with individuals possessing needed competencies for the performance of non-routine jobs. Develop strategic alliances with other providers and share the competencies needed occasionally or for a special targeted project. Give up a measure of control and open traditional boundaries between and among organizations. Share staff resources and skills.

## LANGUAGE FACTORS IN CLINICAL INTERVENTIONS.

It is critically important to have clinical staff speak the same language as the client and, if possible, to have a shared cultural history. Clinicians frequently mis-interpret the behavior of non-English-speaking clients. For example, if a client behaves in a self-effacing manner, the clinician may interpret this behavior as guarded, uncooperative, or that the client feels less intelligent or lacks confidence. Similarly, the clinician may mis-interpret body movements that are efforts to communicate. The clinician may interpret the body movement as motor retardation, depression, physical tension or anxiety.

There are also difficulties associ-

ated with assessing English-speaking clients when that is not their primary language. Speaking a non-dominant language diminishes the speaker's emotional involvement and heightens the likelihood of emotional withdrawal or detachment. The confusion that accompanies times of high stress is heightened when communicating in a non-dominant language is factored into the mix. Clients may give different responses to the same question when asked in their native language and in English. It is critically important to recognize that language is not merely a method of communication; language is also a reality through which individuals perceive and organize their worlds.

Organizations should, if at all possible, avoid using interpreters. On those occasions where interpreters are used, it will be very difficult to establish a sense of bonding between the speakers. The actual content of the interview will be highly dependent on the quality and training of the interpreter. Children and adolescents should never be used as interpreters for their parents as it has the effect of empowering children and disempowering parents. Children are

simply not psychologically prepared for the responsibility placed upon them in the role of translating the kinds of highly personal information that may emerge during a mental health assessment or treatment.

### CULTURAL COMPETENCY INCREASES MANAGED CARE ORGANIZATIONS' COMPETITIVENESS.

Cultural competency improves an organization's ability to engage ethnically diverse consumers and families in a meaningful way and reduces the revolving door syndrome (use of emergency and other more costly services). Cultural competency principles promote provider accountability, coordination and collaboration. Promoting culturally appropriate practice also helps capture Medicaid beneficiaries who would otherwise go to competitors or use the system only at the most costly level of care. Clinical and cultural competency promotes quality care for all clients and assists mental health staff to meet their ethical and professional standards of care.

In sum, culturally competent practice is good for consumers and

providers alike. It recognizes that we all have one or more cultures and acknowledges our emotions, concerns, values and personal principles. Culturally competent practice is personally and professionally rewarding, as well as essential to ensuring a managed care organization's competitive position in today's marketplace.

**JOSIE T. ROMERO, L.C.S.W.**, retired on September 6, 1996 from her position as Division Director, Santa Clara County Mental Health Department.



*Josie Romero*

Josie worked for over 28 years in the field of mental health including serving as Manager of Family and Children's Division. She is now a private consultant in cultural competency planning and staff development. Josie may be reached at: 5253 Edenvale Avenue, San Jose, California 95136; (408) 281-3346 (voice); (408) 229-8327 (fax).

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## A SYSTEM IN TRANSITION: CASSP PRINCIPLES REVISITED

### MANAGED CARE AND CASSP PRINCIPLES.

CASSP (Child and Adolescent Service System Program) system of care values and principles are as relevant in today's managed care environment as they were in the environment of a decade ago. CASSP philosophy has guided states in the development of service delivery for children and adolescents with serious emotional disorders. The CASSP system of care is an ideal system. It includes a comprehensive range of mental health and other necessary services that are organized into a coordinated network to meet the multiple and changing needs of these children and their families. These values and principles were used to bring professionals and parents together to create a common lan-

guage. This commonality guided local communities to change the direction of service delivery to children with emotional disorders and their families. Communities can use the CASSP framework to make sure that managed care models are consistent with the best interests of children and families.

### WHY MANAGED CARE?

Public health, mental health and chemical dependency services are undergoing rapid and profound changes due to managed care. The move of public services into managed care began with the promise it held for states to control the costs of Medicaid services. Managed care has appealed to payers and legislators alike because it focuses on the cost and ef-

fectiveness of government programs. Cost control is clearly a legitimate concern. Any entity that is responsible for making sure that there are enough dollars to appropriately serve each individual under its care must deal with cost. Each provider must be able to afford the services it provides. But without a commitment by (a) key policymakers, (b) parents, (c) advocates, and (d) service providers, to CASSP principles and values, managed care models can be driven by cost alone.

There is no "one" model of managed care. Instead, managed care principles are applied to the specific circumstances of each locale. The challenge to our communities in an era of reduced resources and increasing needs is to be vigilant and stay

## CENTER FOR MENTAL HEALTH SERVICES LAUNCHES MANAGED CARE INITIATIVE

involved in the development of emerging models. States and local communities have the opportunity to shape a locally designed managed system of care that is both cost effective and quality driven. In the public sector, state and local governments have been responsible for the public trust. Governments typically demonstrate that trust through the inclusion of citizens in extensive community planning and evaluation of delivery systems. As new managed care partnerships evolve between the public and private sector, we, the community, must not lose this citizen participation. We must be insistent that our policymakers create formal mechanisms that require continued citizen involvement.

As a child and family system, we must become very proficient in using the tools of managed care to focus on prevention, flexibility, quality improvement processes, effective utilization and outcome-oriented treatment for children and families. The following describes one community's learning about seizing the opportunities and facing the challenges of managed mental health care for children.

### MULTNOMAH COUNTY, OREGON: A CASE EXAMPLE.

Multnomah County, Oregon is a large, diverse, urban community of 631,000 persons. About 80,000 persons live in poverty, half of whom are children. This County has had a long commitment through funding and policy to serve vulnerable children and families. It uses community-established benchmarks to guide policy and financial investments for a healthy and safe community. EPSDT (Early and Periodic Screening, Diagnosis and Treatment) mental health services have been well accessed for Medicaid children and their families. The Multnomah County Partners Project, a recently concluded five year multi-system, multi-partner project, pioneered managing individualized mental health services to children and their families. Services were targeted to 150 children with the highest men-

The Managed Care Initiative is a project designed to support the development of managed care expertise in public sector managed care service administrators and staff. The Initiative, funded through the Center for Mental Health Services and coordinated through the Center for Mental Health Policy and Services Research at the University of Pennsylvania, targets mental health administrators and clinical professionals as the audience for a multi-level intervention of education, planning and cooperative ventures with managed care companies and mental health services. The Initiative is comprised of two components: a central, coordinating project and contracts with five separate professional mental health organizations.

The central project, currently underway, is working to identify, clarify and summarize existing standards of mental health services and clinical competencies for mental health professionals within the parameters of adult services, child and adolescent services, elderly services, services for Hispanic Americans, and services for African Americans. The goal is to identify existing training and educational materials that currently exist for mental health professionals and then to develop additional training materials needed by professionals to practice effectively with these populations within the context of managed care.

For general information on the Managed Care Initiative contact: Marian Mullahy, Project Coordinator, Center for Mental Health Policy and Services Research, University of Pennsylvania Medical Center, Department of Psychiatry, 7th Floor, 3600 Market Street, Philadelphia, Pennsylvania 19104-2648; (215) 662-3531 (voice) or (215) 349-8715 (fax). For information specific to the project's focus on child and adolescent services contact: Sybil Goldman, M.S.W., Associate Director, National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center, 3307 M Street, N.W., Washington, D.C. 20007-3935; (202) 687-5000 (voice); (202) 687-1954 (fax).

tal, emotional and behavioral needs. This is the community context in which the County entered into an agreement with the state of Oregon to provide managed mental health care to Medicaid-eligible children.

Oregon is a state that has systematically moved into managed health care for its Medicaid population. As one of several Oregon managed care initiatives, the Oregon Mental Health and Developmental Disabilities Division entered into an agreement with Multnomah County's Department of Community and Family Services to implement a federal waiver (1915B) on April 1, 1996. The Department of Community and Family Services is a large social services delivery agency that provides a broad array of contract and direct services. The federal waiver, called the "Multnomah

CAPCare (Child and Adolescent Plan)," is to provide mental health services to Medicaid-eligible children and adolescents ages 0-20 who live in Multnomah County.

CAPCare is responsible for providing medically necessary 24 hour urgent and emergency care, acute psychiatric inpatient care, assessment and evaluation, outpatient services and case management services. Included in these benefits are flexible service approaches such as wrap-around services that are individualized to the child's treatment needs. CAPCare offers outpatient services through a provider panel of 28 community-based agencies. These services are reimbursed through a discounted fee for service. CAPCare provides acute care services through several hospital systems. These ser-



vices are reimbursed through subcapitation arrangements. CAPCare is the next step in taking what we have learned through the Partners Project and EPSDT system reform and applying these principles to the larger Medicaid population of children and youth.

## WORKING TOGETHER.

The transition process to managed care has required the commitment and patience of the community. Change is difficult and it is never without its bumps. But the change also is an opportunity to work together to use the potential of managed care to create a more flexible, efficient, quality-driven children's system. This transition has involved creating the vision for the system and operationalizing the plan.

Like many public systems, this community had years of experience serving children with serious mental health needs and their families. The Department of Community and Family Services, hereafter referred to as the "Department," asked our community to plan CAPCare with us to design a system of care that could take full advantage of the flexibility of managed care tools. The Department made sure that parents, advocates, mental health, education, child welfare, health, juvenile justice, and providers sat together to design the type of system we wanted. We used CASSP principles as the core framework. Everyone invested hundreds of hours to declare what the vision would be.

But, as the saying goes, "The devil is in the details." As a system, we had to deal with new and challenging demands that ranged from fiscal and budget issues and information exchange to changes in the fundamental values and expectations of delivering care. These challenges included resolving disagreements about reimbursements and payment methods. There were critical information system operations that had to be put into place at the state, at the department, and at the provider agencies to enable CAPCare to run. CAPCare policy and procedures had to be developed that



would establish a common understanding of admission, discharge, and continuing care criteria. It takes time and experience to resolve these types of issues. CAPCare continues to refine its operations as it matures as a system. During this transition, CAPCare's greatest responsibility has been to make sure that children and families continue to receive necessary care.

## INNOVATIVE APPROACHES.

We have seen an opportunity with CAPCare to use the learning from the Partners Project to advance managed care approaches that better serve children who have serious mental, emotional and behavioral disorders and their families. The Department has continued its collaboration with parents and advocates, child welfare, education, juvenile justice and private foundations to develop innovative approaches to coordinated care.

Rooted in CASSP values and principles, the approaches are intended to optimize coordinated service delivery to high need, at-risk children and adolescents whom we all serve in common. At times, it has been difficult to sort through with the partners the impact that CAPCare and managed care in general has had on our systems. Luckily, the partners have a shared history of providing effective care through collaboration and use

this knowledge to keep the process moving. Parents and advocate representatives have played a strong role in this process. They have been unwavering in their commitment to hold CAPCare accountable for how the model would work and improve services to children.

## A SHIFT IN FOCUS.

Managed care is changing the way the community thinks about providing mental health services to children and families. Under managed care, there are financial incentives to underserve children and families. To offset this potential, the CAPCare delivery system must implement quality assurance/improvement processes that monitor under- and over-utilization of care. CAPCare must also continue to educate parents and families so they are informed consumers of managed care. The Department has used its entry into managed care as an opportunity to engage the community of children's mental health providers and other interested persons in looking at best practices and establishing standards of care. This has created a process for the system to look at improving the cost and quality of care to children. By doing this, we obligate the system to look at each child in relation to community standards to see how an individual treatment is fitting the needs for that child and family.

The clinical providers for CAPCare were engaged in developing the authorization of payment process. Prior to CAPCare, mental health services to Medicaid-eligible children in Multnomah County were paid for by the provider billing the state for services on an as-needed basis. Now, Multnomah CAPCare receives a pre-paid capitated monthly payment from the state to provide these services to CAPCare enrollees. The money comes to CAPCare based on an allotment of Medicaid funds for each enrolled child every month. Out of this fund, CAPCare is responsible for providing all medically-necessary services to CAPCare enrollees. CAPCare authorizes payment to the provider



for services to CAPCare enrollees as indicated by medical necessity.

The implementation of CAPCare has imposed a discipline on the department and its provider panel. Both have had to develop quality improvement processes that monitor over- and under-utilization. Providers have experienced pressure to increase efficiencies because of the loss of income from CAPCare's discounted fees for service. The quality assurance/improvement and utilization management processes assure CAPCare is providing medically necessary and appropriate services to each child as the system is developing efficiencies. Clinicians and administrators are learning new skills to become proficient in managed care tools. CAPCare continues to educate and engage parents and families to become active consumers of managed care services.

### THE ROLE OF PARENTS AND ADVOCATES.

Parents and advocates play a critical role while shifts are occurring under managed care. They tell us what works, what doesn't and why. We have found it to be crucial that CAPCare provides parents and other interested persons a regular forum to

ask questions and challenge processes that are developing. CAPCare has sought technical assistance from parents in how to communicate user-friendly written information to families. It also includes parents and other stakeholders as members of the CAPCare quality improvement committee.

The child and family community service delivery system has pockets of excellence where the role of parents and advocates is routinely assured. Parents and advocates are included in planning and advisory committees and clinical care teams. This role is supported through state and county mandates and provider practices. However, we do not yet have broad, routine parent and advocate participation. The opportunity under managed care is to use much needed customer feedback from parents and families to improve services.

### CONCLUSION.

Many states and communities are moving to managed care systems—not only for health, mental health and chemical dependency services—but also for child welfare services. Similarly, there is an emerging trend in long-term care systems to embrace managed care. These changes provide

an opportunity and a challenge to revisit and reaffirm the CASSP philosophy. CASSP principles and values are compatible with the managed care focus on cost, customer satisfaction and quality processes. However, it is vital that a managed care system design to provide services to vulnerable children and families establishes quality goals to create a child-centered, community-based, culturally competent and consumer-driven system.

Parents and advocates have an opportunity to play a critical role in how states and local communities respond to funding and priority changes at the local, state and national level. Stay involved, stay informed and learn as much as you can about this thing called "managed care."

**JUDY ROBISON, M.A., M.S.W.,** *Managed Care Coordinator, Director's Office, Multnomah County Department of Community and Family Services, 421 S.W. Sixth Avenue, Suite*



*Judy Robison*

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## MANAGED CARE IN EVOLUTION: ONE FAMILY'S EXPERIENCES

I am a single parent of two boys, David, 17 and Isaiah, 15, living in Flagstaff, Arizona. We have had extensive involvement with the state-run health care system, from both the medical and mental health perspective. Our first hand experience is that mental health services delivered through managed care better meet the needs of children and their families.

My oldest son, David, was born with the fibula missing in his right leg and a benign, recurring tumor in his left forearm. He wears a prosthesis to compensate for the difference in leg lengths. There is no way to control the growth of the tumor in his arm without taking most of the muscle and damaging the nerves. David has had five operations to con-

trol the growth of the tumor and hundreds of hours of physical therapy to strengthen his arm and hand. We have been able to get whatever David has needed with very few problems. Most of his surgery has been performed locally.

On the other hand, my youngest child, Isaiah, was diagnosed as having a serious emotional disorder at a young age and finding care for him has been very difficult.

When David and Isaiah were 5 and 3 years old, their father and I divorced and I went back to work. Unfortunately, I had to stop working after about a year, because I was constantly being called to the day care center—and later to the school or juvenile detention center—due to Isaiah's behavior.

Services for Isaiah were virtually non-existent. In 1989, at the age of 8, Isaiah ended up in a therapeutic group home in Phoenix, which is about two-and-a-half hours south of Flagstaff. He was there for more than a year until I decided he needed to come home and be with his family more than he needed their treatment.

Under Medicaid, the state of Arizona has delivered health services within a managed care framework since 1982. However, it wasn't until 1990 that mental health services were provided to eligible people under the age of 21.

Under managed care, treatment for David's arm and leg has been no harder to get than with any other insurance company and, basically, we

have been pleased with the quality of the services he has received.

But, prior to 1990, mental health services were delivered under a fee-for-service model. Our providers operated in the traditional way—appointments between 8:00 A.M. and 5:00 P.M., Monday through Friday. In rural areas, such as where we live, personnel and specialty services were limited.

The move to managed care created much chaos because it was implemented so quickly. Parents, providers, and state agencies quickly saw that they had no choice but to work together and plan the best implementation possible. After two years, the dust settled and everyone was a little more comfortable under the new model. It goes without saying that those two years were hell for our children and youth throughout the state.

After suffering through this hell, in early 1992, I decided that I was going to get involved and learn and do as much as I could. I joined M.I.K.I.D., an organization that provides information and advocacy for children with mental health problems.

In September 1993, after a year of negotiation, an intergovernmental agreement was signed between the

five state agencies that serve children and families. The guiding principles for the agreement are that services should be collaborative, flexible, family-focused, community-based and culturally appropriate. My continuing role in the intergovernmental agreement process is to sit on the executive committee that oversees work groups that focus on identified areas of planning and modification.

One of our accomplishments to date has been the development of a single purchase of care contract that allows providers within the state to work under one contract. This differs dramatically from the former system in which providers contracted separately with each agency. With the move toward a single contract, we hope to improve the quality of services delivered to our children and families.

Another successful innovation is the development of an intensive case management pilot program that began operation in October 1995. The pilot program pulls together a team of case managers from various agencies who work together to designate a single case manager for each child and family.

As I stated before, David has been

able to get just about anything he needs. He can get a prosthesis made specifically for him. No one else can benefit from his personally tailored, unique prosthesis. This is the same type of service delivery that I believe our children and youth with mental health needs should have as well. Services must be carefully prescribed and fashioned to the individual. So far I see that, under a managed care model, families have the opportunity for input in treatment planning and service definition, which in turn results in a system that provides for cost efficiency, accountability, individualized treatments and quality outcomes.

Over the last four years Isaiah has been able to receive the individualized treatment that meets his needs—provided within our own community! The progress he has made is just wonderful. Isaiah is a delightful and happy young man.

**TERI SANDERS** is a statewide advocate for M.I.K.I.D., a family organization working with children's mental health issues in Arizona. M.I.K.I.D. advocates for children and youth within all areas of need and offers support and education to families and professionals.

## MANAGED HEALTH CARE MONOGRAPHS AND REPORTS: RESOURCES FOR PLANNERS, POLICYMAKERS AND ADVOCATES

*Systematic Approaches to Mental Health Care in the Private Sector for Children, Adolescents, and Their Families: Managed Care Organizations and Service Providers* (1996), excerpted at pages 1 – 9, is the report of a study of five sites chosen to represent the state of the art in private sector continuums of managed children's mental health care. Authored by Ira S. Lourie, M.D., Steven W. Howe, M.S.W. and Linda L. Roebuck, M.S.S.W., this monograph provides a detailed description of (a) two managed care organizations and (b) three service provider agencies. Each of these organizations has successfully learned to work within a managed care environment and to offer its own managed care mental

health products to children and families. The report may be obtained from: National Technical Assistance Center for Child Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center, 3307 M Street, N.W., Washington, D.C. 20007-3935; (202) 687-5000 (voice).

*Managing Managed Care for Publicly Financed Mental Health Services* (1995) offers an overview of what a publicly financed managed care system may look like. Authors Chris Koyanagi, Ira Burnim, Joseph Manes and Robert Moon emphasize that managed care in the public mental health system is different than that used in employer-based health insur-

ance. In general, the population in the public sector has more serious disability and mental health needs (often compounded by poverty and, even, homelessness) than the privately insured population. Further, the states have final responsibility for people who have no other method of accessing services.

In addition to describing consumer involvement in public mental health systems, *Managing Managed Care* describes possible benefits designs, discusses considerations in structuring a managed care system, reviews financial issues, and describes the need to develop outcome measures that will promote quality services. *Managing Managed Care* may

be ordered from the following: Publications Desk, Bazelon Center for Mental Health Law, 1101 Fifteenth Street, N.W., Suite 1212, Washington, D.C. 20005-5002; (202) 467-5730 (voice); (202) 467-4232 (TDD); (202) 223-0409 (fax).

*Managing Behavioral Health Care for Children and Youth: A Family Advocate's Guide* is the just-published (August 1996) product of a collaborative effort between the Federation of Families for Children's Mental Health and the Bazelon Center for Mental Health Law. Authored by Trina W. Osher (Federation of Families) and Chris Koyanagi and Rhoda Schulzinger (Bazelon Center), this monograph explains the concept of managed care, offers strategies for child and family advocates to become involved in shaping the design of managed care systems, and includes an extensive glossary of phrases used in discussions about managed care. Four handouts are included as appendices with the suggestion that they be disseminated by family advocates to managed care policymakers.

*Your Family and Managed Care: A Guide for Families of Children with Mental, Emotional or Behavioral Disorders* is a clearly written booklet that explains the workings, advantages and pitfalls of managed care. *Your Family and Managed Care*, as well as *Managing Behavioral Health Care for Children and Youth: A Family Advocate's Guide*, are available in English or Spanish and may be ordered from the Publications Desk at the Bazelon Center for Mental Health Law (see above).

*Health Care Reform Tracking Project: Tracking State Health Care Reforms as They Affect Children and Adolescents with Emotional Disorders and Their Families—The 1995 State Survey* describes the results of a baseline survey of states to identify and describe current state health care reforms that include mental health services. The baseline survey also identified technical assistance materials related to developing and implementing health care reforms (such as requests for proposals, capitation rate-

setting methods, and level of care criteria). The Health Care Reform Tracking Project is a five-year project designed to track and analyze state health care reform initiatives as they affect children and adolescents with mental, emotional or behavioral disorders and their families. The 1996 monograph may be ordered from: Research and Training Center for Children's Mental Health, Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, Florida 33612-3899; (813) 974-6419 (voice).

*Finding a Way Through the Labyrinth: Medicaid Managed Care for Children in Southwest Brooklyn* examines issues of enrollment, education, access and the services offered by managed care plans to Medicaid recipients in Southwest Brooklyn. New York City launched a Medicaid managed care project called the Southwest Brooklyn Demonstration (a) to investigate the impact of universal enrollment of Medicaid recipients into pre-paid managed care programs and (b) to meet the requirements of New York's 1991 Managed Care Act. Among other requirements, the Act mandates that one-half of New York State's Medicaid recipients be enrolled in managed care plans by 1997. The report includes key study findings as well as extensive recommendations designed to increase the quality and comprehensiveness of the care provided by the Medicaid Managed Care program. *Finding a Way Through the Labyrinth* may be obtained from the following: Citizens' Committee for Children of New York, 105 East 22nd Street, New York, New York 10010; (212) 673-1800 (voice); (212) 979-5063 (fax).

*What Legislators Need to Know About Managed Care* (1994) addresses four key questions: (1) What is managed care?; (2) What are the types of managed care organizations?; (3) How have states implemented managed care programs; and (4) What is managed care's role in national health care reform? The report profiles five state programs that use managed care strategies. The monograph, authored

by Shelda L. Harden, may be ordered from the following: National Conference of State Legislatures, 1560 Broadway, Suite 700, Denver, Colorado 80202; (303) 830-2200 (voice); (303) 863-8003 (fax).

In June 1996 the United States General Accounting Office released *Health Insurance for Children: Private Insurance Coverage Continues to Deteriorate*. This report to the U.S. Senate's Subcommittee on Children and Families, Committee on Labor and Human Resources examined the following: (a) the decline in health insurance coverage for poor children; (b) the number of children in working families dependent upon Medicaid; (c) the number of uninsured children eligible for Medicaid but not enrolled; and (d) why families of uninsured but Medicaid-eligible children might not be seeking Medicaid coverage for their children.

In an earlier (1995) report to the U.S. House of Representatives' Committee on Commerce, the United States General Accounting Office examined Arizona's experience in implementing a statewide managed care program. More than 14 years ago,

## NEW TELEPHONE NUMBERS FOR PERSONS WITH HEARING DISABILITIES

**E**ffective immediately, individuals with deafness or other hearing impairments may reach the Research and Training Center on Family Support and Children's Mental Health through the Oregon Telecommunications Relay Service. Both TT and voice users can initiate calls through the Relay Service. The toll-free access numbers are: (800) 735-2900 (TTY) and (800) 735-1232 (voice). Please have the Research and Training Center's telephone number ((503) 725-4040) on hand for the Relay Service. If Research and Training Center staff are not immediately available, they will return your call on the Relay Service.



Arizona was the first state to obtain approval from the Health Care Financing Administration (HCFA) to develop and implement a mandatory statewide Medicaid managed care system. *Arizona Medicaid: Competition Among Managed Care Plans Lowers Program Costs* discusses: (1) the program's cost containment experience; (2) the role of health plan competition in the program's cost containment success; (3) the effect of cost containment on beneficiary access to

appropriate care; and (4) lessons about Arizona's cost containment success that could apply to other states' Medicaid programs. The last two reports may be ordered from: U.S. General Accounting Office, P.O. Box 6015, Gaithersburg, Maryland 20884-6015; (202) 512-6000 (voice); (301) 413-0006 (TDD); (301) 258-4066 (fax).

Finally, the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and

Human Services, has produced a number of publications that address managed care issues. Free courtesy copies of these publications are available. A managed care publications list and order form may be obtained from: National Mental Health Services Knowledge Exchange Network, P.O. Box 42490, Washington, D.C. 20015; (800) 789-2647 (voice); or, on the World Wide Web at: <http://www.mentalhealth.org/>

## THE IMPACT OF CHILDREN'S SSI PROGRAM CHANGES IN WELFARE REFORM

The Children's Supplemental Security Income (SSI) program will be dramatically redesigned and children's eligibility significantly reduced as a result of the welfare reform bill passed by Congress and signed by President Clinton on August 22, 1996. The program will be cut by \$8.2 billion and, over the next six years, 315,000 low-income children with disabilities will lose or be denied access to benefits. The Congressional Budget Office (CBO) estimates that 15% of those who lose or are denied access to SSI will also lose eligibility for Medicaid. In Fiscal Year 1995, the children's SSI program served more than 950,000 qualifying low-income children with severe disabilities. Children with mental retardation were the largest single group, representing about 42% of all children enrolled, while another 33% have physical disabilities and 25% have mental disorders.

Children will have to qualify on the basis of a more narrow definition of childhood disability. The bill will repeal the current statutory language on "comparable severity"—the basis of the United States Supreme Court's 1990 *Zebley* decision, requiring the Social Security Administration (SSA) to use an evaluation process for children comparable to the one it uses for adults claiming disability benefits. The Supreme Court directed SSA to



supplement its listing of medical impairments with an individualized assessment of how a child's impairments affects his or her ability to function. The welfare reform legislation establishes a new definition requiring that a child have a "medically determinable physical or mental impairment which results in marked and severe functional limitations" of substantial duration. The new definition may limit eligibility for children with very significant physical or mental functional limitations. It is possible, for example, that children who have a combination of impairments will have more difficulty qualifying if no single condition matches a medical impairment on SSA's listing.

Children will no longer be able

to qualify through an Individualized Functional Assessment (IFA). The welfare reform legislation eliminates the Individualized Functional Assessment (IFA) established after the *Zebley* decision, as of the date of enactment. In an IFA, a state disability examiner determines eligibility by comparing a child's limitations in various areas of daily activity to the activities of children the same age who do not have a disability. In many states, up to one-third of eligible children qualified through the IFA.

Children can now qualify only through the more restrictive medical listings. SSA will re-evaluate each child who qualified through an IFA to determine if he or she will remain eligible through the medical listings.

SSA has one year from the date of enactment to accomplish these redeterminations. The legislation allocates additional administrative funding for SSA to complete them and conduct continuing-disability reviews. Current recipients will continue receiving benefits until either July 1, 1997 or the date of redetermination, if it is later.

Elimination of the IFA has major consequences for children with serious mental, emotional and behavioral disorders. Among children who now qualify through the functional assessment, 44% have a mental illness or serious emotional disorder. SSA data indicate the percentage of children,



within diagnoses, who will lose access to SSI by elimination of the IFA includes: (a) 49% of the children who qualify because of mood disorders; and (b) 22% of those children who have schizophrenia.

The IFA generated much of the controversy about the program because critics alleged that parents coach their children to fake mental disorders. These allegations prompted several examinations of the program by SSA, the Health and Human Services Office of Inspector General and the General Accounting Office. While they criticized some aspects of the program, none of the investigators were able to substantiate allegations of widespread fraud. CBO estimates that 267,000 children will lose access to benefits over the next six years as a result of the IFAs elimination.

The medical listings will be modified to eliminate references to "maladaptive behavior" when evaluating personal/behavioral functioning for children with mental impairments. Under the mental impairment listings, maladaptive behavior may be counted both in the domain of social functioning and in the domain of personal/behavioral functioning. Contrary to anecdotal reports, the current disability evaluation process has not allowed children to qualify solely on the basis of a mental diagnosis and evidence of maladaptive behavior. However, despite advocacy on this issue, the legislation eliminates use of such evidence in one part of the mental impairment listings. CBO estimates that, over the next six years, another 48,000 children will lose access to benefits as a result of this change in the mental impairment listings.

Up to 50,000 children will lose access to health care through the Medicaid program. Children who lose their SSI benefits will continue to receive Medicaid if they can remain eligible on other grounds, such as their age and their family's low income. Coverage of low-income children through age 13 is now guaranteed and mandatory coverage of older children is being phased in through 2002. Children with severe disabilities who

lose their Medicaid eligibility will face tremendous uncertainty. Many families will simply not have the resources to care for them at home. Many will have to turn to state and local governments for assistance. Especially tragic is the likelihood that more families will be forced to surrender custody to get care for their children, either through the foster care system or in state institutions—at far higher cost to taxpayers. And without the federal dollars that parents now spend on their children's behalf, states' costs to serve children with severe disabilities will escalate.

More frequent reviews of disability. The legislation mandates continuing-disability reviews every three years for all children except those whose conditions are not expected to improve. The child's representative payee will have to show evidence, at the time of the review, that the child is receiving treatment to the extent medically necessary and available for the qualifying condition. For children who qualify because of their low birth weight, it requires reviews 12 months after birth. And within one year after a child's 18th birthday, it requires review under adult eligibility criteria.

Dedicated savings account. The legislation requires the parent to establish an account for any back benefits that exceed six times the maximum monthly payment. This money may be used only to cover specific expenses, including education or job-skills training, personal-needs assistance, special equipment or housing modifications, medical treatment, therapy or rehabilitation, and other items or services that SSA has determined are appropriate.

Reduced benefits for hospitalized children with private insurance. The legislation requires that children who are hospitalized, whose medical care is covered by private insurance, receive no more than the \$30 monthly SSI benefit paid to children whose medical bills are covered by Medicaid.

New regulations. The legislation requires SSA to develop new regulations for the children's SSI program

within three months after enactment.

Annual reports. The legislation requires SSA to provide an annual report on the SSI program to the President and Congress, including historical data on prior enrollment by public assistance recipients.

GAO study. The legislation requires a study by the General Accounting Office on the impact of the new children's SSI provisions and the extra expenses incurred by families of children receiving benefits that are not covered by other federal, state or local programs.

Current status. The children's SSI program now provides eligible children up to \$470 a month and, in most states, access to health care through Medicaid. The money helps many families meet their child's need for special food, clothing, equipment, transportation, unreimbursed medical expenses and child care—including care by a parent who cuts back on work to provide it.

At various times during the welfare reform debate, families faced the threat of losing this cash assistance—either through its replacement by vouchers for state-provided services or by a 25% reduction in benefits for certain children. Fortunately, the children who remain eligible will continue to receive the critical support of cash assistance.

Recently, the allowance rate for children applying for SSI benefits has declined to a rate lower than it was before the *Zebley* decision. Data from the Social Security Administration show that the allowance rate, which was 43% prior to the *Zebley* decision, had fallen to 32% in 1995 and continued its drop during the first four months of 1996, to 31%.

SOURCE: *Bazelon Center for Mental Health Law*, 1101 15th Street N.W., Suite 1212, Washington, D.C. 20005-1212; (202) 467-5730 (voice); (202) 467-4232 (TDD); (202) 223-0409 (fax).

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## NATIONAL COMMITTEE FOR QUALITY ASSURANCE LAUNCHES BEHAVIORAL HEALTH ACCREDITATION PROGRAM

The National Committee for Quality Assurance (NCQA) is an independent not-for-profit organization dedicated to assessing and reporting on the quality of managed care plans, including health maintenance organizations (HMOs). NCQA is governed by a board of directors that includes employers, consumer and labor representatives, health plans, quality experts, regulators and representatives from organized medicine. NCQA recently launched a Behavioral Health Accreditation Program that aims to assess the quality of managed behavioral health care service delivery.

Upon implementation, the standards will be used primarily to review managed behavioral health care organizations. Managed care organizations that provide behavioral health services will continue to be reviewed under NCQA's MCO Accreditation Standards, but will also be given the option of having their behavioral health programs reviewed under the Behavioral Health Standards. After three years, NCQA anticipates that all managed behavioral health programs will be assessed against the Behavioral Health Standards.

The draft standards mark the first national effort to assess the quality of managed behavioral health plans, but the standards also incorporate the work of several large, national employers who have, individually, developed criteria by which to examine the quality of managed behavioral health care organizations. For additional information concerning the draft national accreditation standards for managed behavioral health organizations contact: National Committee for Quality Assurance, 2000 L Street, N.W., Suite 500, Washington, D.C. 20036; (202) 955-3500 (voice); (202) 955-3599 (fax); <http://www.ncqa.org> (World Wide Web).

## FAREWELL STAFF MEMBERS!

We would like to recognize five Research and Training Center staff members who have recently left the Center. After twelve years with the Research and Training Center, James Mason, the Center's director of training and principal investigator for the Increasing Multicultural Parent Involvement project, has accepted a position with the Oregon Health Sciences University. James is coordinating the Oregon Health Professions Partnership Initiative. This new initiative is an innovative plan to improve educational opportunities for people of color and women interested in the health professions. James' new role involves promoting close cooperation between high school students participating in a health science/biotechnology magnet program and higher education health-related programs. Fortunately for the Center, James will continue to be available to us as a consultant on diversity issues and will continue to teach a course within Portland State University's School of Social Work.

Denise Stuntzner-Gibson and her family recently moved to Roseburg, Oregon. Denise served as the project manager for the Effects of Family Participation in Services: A Panel Study project. That project evaluated a five year intervention funded by the Robert Wood Johnson Foundation that included case management services plus flexible funding to serve children with serious emotional disorders. Denise has happily returned to her small town, rural roots. Denise accepted a position with a social service organization that provides short-term, intensive services to families who have been identified as "at-risk" within the child welfare system.

Katie Schultze recently retired after twelve years with the Research and Training Center and 23 years with the Regional Research Institute for Human Services. Most recently Katie served as the project manager for the Family Participation in Residential Treatment Programs project. Her other hats have included coordination responsibilities for a number of the Center's conferences and a variety of administrative duties. Katie's so-called "retirement" includes ongoing social services consulting work and extensive travel plans. Shortly before retiring Katie traveled to Ethiopia and Mexico, and now has plans to visit Portugal.

Harold Briggs and Solla Carrock have also just left the Research and Training Center. Harold and Solla served as, respectively, the principal investigator and the project manager for the National Evaluation of Statewide Family Support Networks project. That evaluation project tracked the development of 28 statewide family support networks across the country. We will continue to regularly see Harold as he is continuing his work as an associate professor in the Graduate School of Social Work. Harold is thoroughly enjoying teaching: "I just love teaching!" He is spending more time with his wife and son and is working to increase the balance in his life between work and family.

Solla accepted a position as a tester with a software company. She is continuing her coursework and will receive her computer science degree in December. Solla also meets weekly with a writer's group and is diligently pursuing her interest in creative writing. Solla said, "What I enjoyed the most about my position with the Research and Training Center was the opportunity to talk with family members."

We wish all of these individuals the best in the future and are grateful that we had the opportunity to work with them.

## CENTER FOR MENTAL HEALTH SERVICES FUNDS STUDY OF RURAL MANAGED CARE SERVICES

On October 1, 1996 the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, awarded nearly \$1,350,000 to Portland State University's Regional Research Institute for Human Ser-

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vices to conduct a three year study that will examine rural managed care health services. At present, very little information is available about the impact of managed care on children with serious emotional disorders and Medicaid clients served by rural community mental health agencies. The capitated managed care plan to be studied is administered by Greater Oregon Behavioral Health, Inc. This system operates in rural Oregon, serves some 35,000 covered individuals and has been in operation as a prepaid Medicaid provider for almost two years.

The study is designed to: (1) determine whether outcome differences exist between recipients of prepaid versus fee for service health care; (2) compare the linkages with primary care providers made by prepaid mental health providers with those made by fee-for-service mental health providers; (3) compare prepaid and fee-for-service clients' usage of hospital and residential services; and (6) compare expenditures of prepaid mental health providers and fee-for-service systems providers. For further information on this project contact: Robert I. Paulson, Ph.D., Regional Research Institute for Human Services, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751; (503) 725-5195 (voice); (503) 7254180 (fax); or E-mail paulsor@pdx.edu

## NEW CHILDREN'S MENTAL HEALTH RESOURCES

*Children's Mental Health: Creating Systems of Care in a Changing Society* (1996) is the newly published anchor of a book series entitled *Systems of Care for Children's Mental Health*. Edited by Beth A. Stroul, M.Ed., and including a foreword by Rosalynn Carter, *Children's Mental Health* thoroughly discusses current philosophies, trends and practices in children's mental health. This volume examines: (1) the philosophical underpinnings of the system of care concept and the values and principles that should guide service delivery; (2) system development efforts undertaken at federal, state and local levels; (3) management issues affecting the development, operation and evaluation of systems of care; (4) family involvement in all aspects of service planning and delivery within systems of care; (5) specific service delivery approaches for various subpopulations of youth; and (6) the issues and challenges facing systems of care in the future.

*What Works in Children's Mental Health Services? Uncovering Answers to Critical Questions* (1996) is the third volume in the *Systems of Care for Children's Mental Health* book series. Edited by Krista Kutash, Ph.D. and Vestena Robbins Rivera, M.A., this book offers policymakers, service providers and related professionals a comprehensive overview of recent research in the field of children's mental health. This volume describes studies that have been conducted on each of the following components of a coordinated network of services: (1) outpatient services; (2) home-based services; (3) crisis and emergency services; (4) case management/service coordination; (5) day treat-

ment; (6) therapeutic foster care; (7) residential services; and (8) family support services. This concise book also evaluates the methodology of the studies, analyzes their results, and summarizes the findings for each individual component.

The above two books as well as the first volume in the series, *From Case Management to Service Coordination for Children With Emotional, Behavioral or Mental Disorders: Building on Family Strengths*, are available from the Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, Maryland 21285-0624; (800) 638-3775 (voice); (410) 337-8539 (fax).

*Emerging School-Based Approaches for Children With Emotional and Behavioral Problems: Research and Practice in Service Integration* (1996) features conceptual, practice and research issues relevant to school-based integrated service programs for children and youth with emotional and behavioral disorders. The topics addressed include: (1) an analysis of the National Agenda for Children and Youth With Emotional and Behavioral Disorders; (2) structuring schools to become primary delivery sites for a range of health and social services; (3) descriptions of exemplary programs from across the country that have as their focus the integration of services; and (4) the challenges and opportunities of involving families in change processes in schools. *Emerging School-Based Approaches* may be ordered from: The Haworth Press, Inc., 10 Alice Street, Binghamton, New York 13904-1580; (800) 342-9678 (voice); (800) 895-0582 (fax).

## CALL FOR PAPERS

The Research and Training Center for Children's Mental Health is now accepting applications to present at their tenth anniversary conference on service system research. The national conference, *A System of Care for Children's Mental Health: Expanding the Research Base*, will be held on February 23-26, 1997 at the Hyatt Regency Westshore in Tampa, Florida.

For the past decade, this national conference has explored current research methods and findings regarding emerging systems of care and policy for children emotional and behavioral disorders and their families. For the tenth annual conference, 600 researchers, evaluators, administrators, policymakers, advocates and family members will come to Tampa Bay to learn how the research base can be used to strengthen service systems in their communities.

The Center will consider proposals for paper presentations (30 minutes) and poster presentations, and encourages proposals for symposia (90 minutes) that combine several presentations related to a single study or topic area. The deadline to submit applications to present is October 30, 1996.

Typical topics will include: (1) characteristics of children receiving services; (2) service system development and assessment; (3) treatment and program evaluations;



# NOTES & COMMENTS

(4) organization, staffing and financing of service systems; (5) policy development/change initiatives; (6) accountability and managed care; (7) research and evaluation of services; (8) research in the education system; and (9) studies on child welfare/foster care systems.

The Research and Training Center for Children's Mental Health is part of the Department of Child and Family Studies at the University of South Florida's Mental Health Institute. The Center is federally funded by the Center for Mental Health Services and the National Institute on Disability and Rehabilitation Research.

To request submission information and instructions contact: Krista Kutash, Ph.D., Deputy Director, Research and Training Center for Children's Mental Health, Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, Florida 33612-3899; (813) 974-4661 (voice); (813) 974-6257 (fax); or [kutash@hal.fmhi.usf.edu](mailto:kutash@hal.fmhi.usf.edu) (e-mail).

## BI-ANNUAL TRAINING INSTITUTES HELD IN MICHIGAN

The Grand Traverse Resort in Traverse City, Michigan was the site for the recent children's mental health Training Institutes. The bi-annual event, held June 9-13, 1996, and entitled *Developing Local Systems of Care in a Managed Care Environment for Children and Adolescents with Serious Emotional Disturbances*, attracted approximately 1300 participants from across the United States. General sessions examined, from a variety of perspectives, the growth of managed care and its potential implications for systems of care, issues facing children and families and current directions in our national policy.

Featured speakers included Keith Schafer, vice president of Government Programs of Value Behavioral Health, a managed behavioral health company serving over 21 million people (where his role is assisting government agencies as they move into the managed care environment) and Geoffrey Canada, president and chief executive officer of New York City's Rheedlan Centers for Children and Families and author of *Fist Stick Knife Gun: A Personal History of Violence in America*.

In addition, workshops focused on a range of issues related to system development such as educating the public about children's mental health, roles for families in systems of care, accountability in systems of care, leadership, family involvement in managed care, and involving youth in systems of care.

The Institutes are sponsored by the National Technical Assistance Center for Children's Mental Health at Georgetown University and are funded by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. For more information contact the National Technical Assistance Center for Children's Mental Health at 3307 M Street, N.W., Washington, D.C. 20007; (202) 687-5000 (voice); (202) 687-1954 (fax).

## FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH SCHEDULES EIGHTH ANNUAL CONFERENCE

The Federation of Families for Children's Mental Health will hold its eighth annual conference November 15-17, 1996 at the Crystal Gateway Marriott Hotel in Arlington, Virginia. The conference, entitled *Ahead of the Curve: Maximizing Learning Opportunities for Children and Youth With Emotional, Behavioral or Mental Disorders*, will feature a keynote address by Jonathan Kozol, author of *Amazing Grace*. Kozol is a long-time child welfare advocate. His newest book, *Amazing Grace*, is a report from one of the poorest places in the nation, New York's South Bronx. A limited number of scholarships are available to make it possible for families from all ethnic and cultural backgrounds, all economic circumstances, and all geographic regions of the country to participate in the Federation's annual conference. For additional conference information contact: Federation of Families for Children's Mental Health, 1021 Prince Street, Alexandria, Virginia 22314; (703) 684-7710 (voice); (703) 836-1040 (fax); <http://www.mindspring.com/~bcfamily/> (World Wide Web).

## NEW MENTAL HEALTH INFORMATION CLEARINGHOUSE ANNOUNCED

The Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Mental Health Services (CMHS) recently launched the National Mental Health Services Knowledge Exchange Network (KEN)—a one-stop source of information and resources on mental health. KEN offers a traditional helpline for information and referrals through a toll-free telephone service ((800) 789-2647). The public can also reach KEN online, either through its World Wide Web site on the Internet (<http://www.mentalhealth.org>) or through its electronic bulletin board service ((800) 790-2647), which is accessible via computer and modem.

KEN was created to provide ready access to mental health information and resources to users of mental health services, their families, the general public, and those who design, deliver or finance mental health services. "Mental illness is one of the most significant health problems in America," said SAMHSA Administrator Nelba Chavez, Ph.D. "At the same time, it is one of the most treatable illnesses. Unfortunately, many people are not getting the help they need—often because they do not know where to go for help. KEN is a way to put people in touch with the information and referrals they need."

KEN's toll-free helpline and online resources provide linkages and referrals to more than 1,600 consumer and family advocacy organizations; federal, state and local mental health agencies; mental health organizations and associations; national clearinghouses and information centers; and sixteen CMHS technical assistance centers that address special issues related to mental health services.

# PUBLICATIONS

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- FAMILIES AS ALLIES CONFERENCE PROCEEDINGS: PARENT-PROFESSIONAL COLLABORATION TOWARD IMPROVING SERVICES FOR SERIOUSLY EMOTIONALLY HANDICAPPED CHILDREN & THEIR FAMILIES. 1986. Delegates from thirteen western states. \$1.00.
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- NEXT STEPS: A NATIONAL FAMILY AGENDA FOR CHILDREN WHO HAVE EMOTIONAL DISORDERS (BOOKLET). Designed for use in educating about children's mental health issues. Single copy: \$2.50. Five Copies: \$7.00.
- ORGANIZATIONS FOR PARENTS OF CHILDREN WHO HAVE SERIOUS EMOTIONAL DISORDERS: REPORT OF A NATIONAL STUDY. Study of 207 organizations for parents of children with serious emotional disorders. \$4.00.
- PARENT-PROFESSIONAL COLLABORATION CONTENT IN PROFESSIONAL EDUCATION PROGRAMS: A RESEARCH REPORT. Results of nationwide survey of professional programs that involve parent-professional collaboration. Includes descriptions of individual programs. \$5.00.
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# PUBLICATIONS

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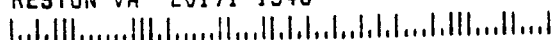


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