COMMUNITY SYSTEMS OF CARE FOR CHILDREN'S MENTAL HEALTH

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INTRODUCTION

Community mental health services for children and adolescents have undergone a major revolution in philosophy, practice, and research in the last 20 years. The traditional community mental health consultation model, prevalent from the 1950's to the mid 1980's, is increasingly being replaced by the more comprehensive community systems of care philosophy and model. This model is based on a flexible and individualized approach to service delivery for the child and family within the context of his/her home and community as an alternative to treatment in out-of-home settings, while attending to important family and systems issues. This paper reviews the factors that led to the development of this new model, the principles and implementation of this model, the evidence-base behind the model and its interventions, and unique challenges in children's mental health that it addresses.

CONTINUING CRISIS IN CHILDREN'S MENTAL HEALTH SERVICES

Recent studies suggest overall prevalence rates for childhood mental illness of 15 to 19 percent, with 3 to 8 percent for serious mental illness and emotional disturbance. A number of morbidities have been associated with childhood emotional disturbance and mental illness, including suicide, homicide, substance abuse, child abuse, teenage pregnancy, school dropout, youth crime, and associated institutionalization and incarceration. However, less than one percent of children in the United States receive mental health treatment in hospital or residential settings and another five percent in outpatient or community settings, with most children in need receiving insufficient or no mental health services. In contrast, the budgets dedicated to the financing of public mental health services for children have grown exponentially since the 1970's. For example, total Medicaid expenditures for mental health (largely applied to children) will grow to an estimated 14 billion dollars by 2010, comprising a large portion of the total national mental health budget. A disproportionate level of these expenditures have been dedicated to inpatient and residential treatment, which are viewed with increasing skepticism given their high cost and limited evidence-base (U.S. Department of Health and Human Services, 1999).

The great majority of children served by Medicaid are poor, undeserved children, many from minority backgrounds. These children experience higher levels of stressors, such as poverty, discrimination, immigration, acculturation stress, and exposure to violence and trauma, and are likely to have higher levels of need for services. The cost of serving these populations of children and adolescents is in contrast to the high cost of their future psychosocial morbidity, including lost productivity and the costs of welfare dependency and institutionalization. A number of child serving agencies (schools, social welfare agencies, child protective agencies, juvenile justice, public health) are experiencing the increasing impact of psychosocial morbidity and lack of services experienced by undeserved children and youth. These agencies typically address pieces of the service system puzzle with little to no coordination with each other, while often serving the same youth (Pumariega, et al., 1997).

These trends have increased pressures on public child mental health and social service agencies to demonstrate improved clinical- and cost-effectiveness, increasingly turning to managed care approaches to finance and organize mental health and social services. For example, approximately 52% of children who are Medicaid beneficiaries are under managed care plans, the largest beneficiary group in these programs. However, most managed care approaches were developed with adult and private sector populations in mind. When applied to public child mental health services, these approaches have often resulted in fragmentation of care and the shifting of the burden of services and cost to the other child serving agencies and systems, with the potential for significantly increased morbidity. Over the past 10 years, there has been an exponential growth of class action lawsuits against state Medicaid, educational, child welfare, and juvenile justice agencies for failing to meet Federal mandates as a result of such cost- and burden- shifting. (Pumariega, et al., 1997; Vaughan, Pumariega, & Klaehn, 2003).

The modern era of community-based systems of care for children was ushered in by the publication of Jane Knitzer's (1982) groundbreaking book, Unclaimed Children, which exposed the aforementioned consequences of neglecting the provision of community-based mental health services for children and their families. Her advocacy and that of others led to the development of the Child and Adolescent Service System Program (CASSP), which assisted all 50 states in the development of an infrastructure for publically funded community-based services. The CASSP initiative was supported by the conceptual work of Stroul and Friedman (1986), who coined the term "community-based system of care for seriously emotionally disturbed

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children" and enunciated the principles behind such systems of care. Stroul and Friedman's work spurred the development of various innovative community-based treatment modalities as well as a number of model demonstration programs in different parts of the United States that exemplify the use of these modalities within the context of an organized inter-agency system of care. In the early 1990's, the Robert Woods Johnson Foundation established eight pilot demonstration community systems of care programs in different parts of the country that demonstrated the viability of the system of care approach and demonstrated cost-savings as well as less restrictive levels of care. Starting in 1994, the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration established the Comprehensive Community Mental Health Services for Children and their Families Program. This program has funded over 70 community systems of care sites throughout the nation in widely diverse communities and American Indian communities, with over 50,000 children and families served by them, accompanied by a national evaluation. The Surgeon General's Report on Mental Health (U.S. Department of Health and Human Services, 1999) focused its recommendations for children's mental health around the system of care model and its benefits for service system reform and individualized care.

THE COMMUNITY SYSTEMS OF CARE MODEL

The CASSP initiative set forth the initial principles inherent in community-based systems of care. The key principles include: access to a comprehensive array of services, treatment individualized to the child's needs, treatment in the least restrictive environment possible (with full utilization of the resources of the family and the community), full participation of families as partners in services planning and delivery, interagency and interdisciplinary coordination, the use of case management for services coordination, no ejection or rejection from services due to lack of "treatability" or "cooperation" with interventions, early identification and intervention, smooth transition of youth into the adult service system, effective advocacy efforts, and non-discriminating, culturally sensitive services.

Assessment and treatment within the systems of care model are designed to support consumer families in having true access to care, that involves not only assuring quality of services, but also services that are relevant to the family. A primary goal of a system of care is to empower families to assume full responsibility for their child's care, and to be full participants in the process of care planning. It is the professional's responsibility to individualize treatment plans and approaches to the unique needs of each child served. Some children and youth enter the system of care with discrete problems that can be addressed by a specific and/or time limited service. In more complex situations, assessment and treatment planning should be accomplished through inter-disciplinary clinical teams. Child and adolescent psychiatrists should be included as members of these teams. The emphasis within these teams should be on the child and family's strengths, addressing specific clinical needs and supporting the child in his/her family and community environment. Mobilizing normative resources such as recreational and extracurricular school based programs assures that the child is fully included in the life of the community and developmental and clinical needs and strengths are addressed.

Systems of care principles are most applicable to children and youth with complex problems and who require services across agencies. The overriding principles involve full family inclusion in assessment and care planning, while assuring that all services are coordinated and delivered in the least restrictive setting. There are several models that have been developed around the country that strive to adhere to these principles. Some system of care programs emphasized the creation of interagency collaboration teams that assist families and professionals from involved agencies to collaborate in forming a single care plan. This model emphasizes the need for a single case manager who will monitor the collaborative efforts. Some of the interagency agreements for such teams provide for pooled "flexible funds" that enable the teams to provide for critical needs that would never be addressed in a conventional care system. Many families can be well served by such interagency collaborative efforts, but often a parent or a youth surrounded by a team of professionals finds the experience intimidating and have trouble feeling that they are full participants in the planning process (Winters & Terrell, 2003).

The wraparound process is a more family-centered approach to system of care principles that redefines the relationship of the family to the system of care. Central to this process is the development of a Child and Family Team (CFT). The goals for team development are to mobilize the natural support system for the family, including extended family, friends, neighbors, and natural helpers in communities. CFT's may include professionals to whom families have come to feel close to, but generally teams should include no more than 50% professionals. Teams should employ professional advisors, including child and adolescent psychiatrists, who can offer advice on services, how best to access them, and on the various agencies in which the child is involved. Helping consumer families become sophisticated and empowered involves a process of support, education, and respect (Huffine & Anderson, 2003). The most complete evolution of a system of care that supports family-centered care involves agencies blending funds and undoing categorical constraints on the use of funds, with CFT's having control over the expenditure of such funds for services they deem needed and relevant. This radically alters the relationships of service providers to consumer families, enabling poor families to have similar control as middle or upper-class families in their child's care and encouraging programs to develop new types of resources based on the common needs of families in that community.

Given the complexity of systems of care, the skills and roles that professionals must display go far beyond their circumscribed clinical. Child and adolescent psychiatrists, given their broad biopsychosocial and developmental perspectives, are able to integrate and coordinate community-based treatment delivered by multiple professionals with diverse skills, but they must develop collaborative and consultative skills to effectively serve within such systems. There is also a need for different professional roles for other disciplines and

professionals. Social workers and other masters' level professionals assume a collaborative and partnership role serving as case managers and therapists. Psychologists are involved in the implementation of newer evidence-based practices, such functional behavioral analysis and systematic measurement of behavior and strengths along with their psychodiagnostic and therapeutic roles. Nurses are have greater involvement as psychiatric extenders (or, in some states, as primary psychiatric providers) as well as serving in liaison roles to pediatric and health systems. Community systems of care also have important roles other child serving professionals such as educators, recreational and occupational therapists, juvenile justice and child welfare staff, and others in implementing individualized service plans in community settings (American Academy of Child and Adolescent Psychiatry, 1996).

As discussed previously, the child and family members should be full participants in the care process, with shared responsibility with care managers and family advocates for selecting and coordinating services as well as utilizing them. This supports the development of respect for the family's autonomy and values. However, the concept of family and consumer empowerment has been extended beyond the treatment setting to include their participation in a number of other roles within systems of care. These include providing case management and support services to other families, serving in quality assurance and consumer satisfaction assessment, participating in governance over system of care programs, and advocating for the maintenance and expansion of these programs. Organizations such as the Federation of Families for Children's Mental Health and other advocacy groups are helping to move the family and youth advocacy agenda. (Huffine and Anderson, 2003).

CULTURALLY COMPETENT SERVICES: SPECIAL NEEDS OF MINORITY YOUTH

The Surgeon General's Supplement on culture, race, ethnicity, and mental health (U.S. Department of Health and Human Services, 2001a) has highlighted the serious racial/ethnic disparities in child mental health and social services in our nation. For example, African American children tend to remain in foster care for longer period of time and to have more foster care placements than European American children. Studies have shown culturally diverse children to be under-represented in mental health institutions and over-represented in child welfare and juvenile justice settings and placements compared to non-minority youth, even when they are equally psychiatrically impaired. Ethnic and racial disparities in the diagnosis, prevalence of disorders, and services and treatment utilization by culturally diverse youth have been identified in many studies. Studies have also shown higher retention in treatment of minority youth if the clinician is of a similar ethnic/ racial background (Pumariega, 2003).

The principle of cultural competence is an integral aspect of community-based systems of care philosophy (Cross, Bazron, Dennis, & Isaacs, 1989). It proposes that practitioners in systems of care develop the necessary attitudes, skill, and knowledge base to serve minority and culturally diverse children and families in their communities, as well as policies and procedures be developed within these systems to remove barriers for access to services and make these more responsive to the values of diverse communities. The community-based systems of care approach is congruent with the cultural values of ethnic minority populations, which emphasize strong extended family involvement in the life and upbringing of children and the use of natural community resources first in dealing with the emotional and physical problems of family members (Pumariega, 2003).

EVIDENCE-BASE FOR COMMUNITY SYSTEMS OF CARE AND MODALITIES

Outcome data on early system of care demonstration projects in Vermont, New York, Ventura County, California, and the eight Robert Woods Johnson pilot sites demonstrated reduced hospitalization rates and days, decreased out-of-home placement and less restrictive placements, significantly lower incidence of negative behaviors placing them at-risk out-of-home placement, and significantly lower rates of overall problem behaviors (Ichnose, Kingdon, & Hernandez, 1995; Bruns, Burchard, & Yoe, 1995; Evans, Armstrong, & Kuppinger, 1996). The Robert Woods Johnson pilot sites also demonstrated significantly lower costs using a managed sub-capitation approach for funding flexible services for children with serious emotional disturbances. (Winters, Marx, & Pumariega, 2003). The evaluations of the CHAMPUS-funded Fort Bragg Demonstration Project (a comprehensive continuum of care for the children of military dependents at Fort Bragg, North Carolina) and the Stark County CMHS demonstration site, compared their outcomes to those of usual service sites. These programs achieved significantly lower restrictiveness of care, higher family and consumer satisfaction, greatly increased access to services, and greater funding spent in less restrictive services. However, clinical and functional outcomes were not significantly different overall, with split differences in different diagnostic sub-groups and overall outcomes being no different. Additionally, costs were not significantly different and possibly even somewhat higher in the demonstration site. Critics of these studies have asserted that these studies were limited by their lack of comparability of the populations served, lack of long-term follow-up, and lack of accounting for cost offsets from the impact of illness in calculating costs of care (Bickman et al., 1996).

The Comprehensive Community Mental Health Services for Children and their Families Program, funded by the Center for Mental Health Services, has by now funded 67 community-based systems of care model sites throughout the United States, serving over 52,000 children since 1994. Children and youth in these system of care programs have had significant results in: improved child behavior, improved child functioning, fewer contacts with law enforcement, increased stability in living situation, improvements in child and family strengths and resources, reduced caregiver strain, and improved family function. Of children who entered these programs being placed in out-of-home residential placements, over 50%

were living with parents, relatives, or friends at the six-month follow-up, thus significantly reducing out-of-home placement. Preliminary results demonstrate reduced cost of care within these programs when indirect cost offsets are considered, such as child welfare, juvenile justice, educational, and general health costs (Holden, et al., 2003).

The recent Surgeon Generals report on mental health (1999) and on youth violence (2001b) point to research evidence supporting the effectiveness of a number of community-based interventions for children and youth, such as intensive case management, therapeutic foster care, partial hospitalization, and intensive in-home wraparound interventions. Other community-based interventions which show promise include school-based interventions, mentoring programs, family support and education programs, wilderness programs, crisis mobile outreach teams, time-limited hospitalization with coordinated community services, and family support services (Burns & Hoagwood, 2002; Rogers, 2003). Studies involving these modalities have demonstrated significantly better outcomes than traditional outpatient or residential services. These include reduced levels of externalizing and internalizing symptoms, improved family functioning, reduced utilization of more restrictive services, and improved cost-effectiveness. Additionally, a number of in-home preventive parent-child interventions with infants and young children have demonstrated long-term effectiveness in reducing child abuse as well as adverse behavioral and academic outcomes (Olds, Henderson, Tatelbaum, & Chamberlain, 1986; Zeanah, et al., 2001). On the other hand, there is a lack of research evidence or actual lack of effectiveness for a number of more restrictive interventions, such as inpatient hospitalization, long-term residential treatment, therapeutic group homes, and boot camps (U.S. Department of Health and Human Services, 1999, 2001b).

The wrap-around approach is the essence of systems of care interventions and services. This model emphasizes aggressive outreach, use of least restrictive treatment options, and individualized, flexible, and unconditional child and family centered services for children imminently at-risk or already in out-of-home placements. Wrap-around plans can build a level of service intensity rivaling that of inpatient or residential settings without removing a child from his/her home. A number of studies of wrap-around programs in different communities across the nation with diverse populations of at-risk children and families have reported positive outcomes in terms of reduction of externalizing behavioral problems, level of function, reduction in out-of-home placement, improved family management skills and function, and consumer/family satisfaction (Burns, Goldman, Faw, & Burchard, 1999).

Multisystemic therapy (MST) combines home-based, wrap-around, and cognitive-behavioral interventions within a systemic context. It has been evaluated with youth at-risk of detention/ incarceration and at risk of psychiatric or substance abuse hospitalization, with significant results in reducing out-of-home placement, reducing externalizing problem behaviors, reducing rates of recidivism, and lower costs of treatment (Henggeler et al., 2002).

One of the major challenges faced by community-based systems of care programs is the integration of evidence-based treatment modalities within them. There are numerous manualized individual and family therapies, primarily based on cognitive-behavioral, interpersonal, and behavioral models, that have established results in treating children with a range of disorders (Rogers, 2003). There is a similar growing literature in the use of pharmacological interventions with children (Pumariega & Fallon, 2003). The challenges around the use of such modalities in systems of care are around their integration and systematic implementation within these programs while preserving system of care principles. This includes the use of multi-informant systematic assessment and measures to establish diagnoses and evaluate target symptoms, and the integration of trained professionals (psychiatrists and psychologists) in the assessment, care planning, and follow-up of children served within these systems. Education of and empowerment of youth and families is critical to a true informed and participatory approach to psychopharmacological interventions in systems of care. Education for and coordination with other disciplines is also critical to this integration. Attention to ethnic and cultural factors in diagnosis, metabolism of pharmacological agents, acceptability of different therapeutic modalities, consent procedures, and perceptions of such modalities are also important (Pumariega, & Fallon, 2003).

CHALLENGES FOR COMMUNITY-BASED SYSTEMS OF CARE

Community-based systems of care for children's mental health face a number of challenges. Some of these are inherent to the ambivalence about social services programs and budgets that is inherent in American society today, with its mistrust of government and orientation to low tax burdens. Some of these challenges are specific to the challenges faced by service agencies and systems that comprise community-based systems of care.

The movement to managed behavioral health care has provided both a challenge and an opportunity for application of community-based systems of care principles. The stated objectives of managed care—providing care in the least restrictive environment, reinvesting revenue saved from decreased use of higher levels of care into community-based and preventive care, and achieving quality of care through outcome accountability—are very compatible with the principles of systems of care. System of care principles could even be seen as embodying a "true" managed care philosophy. For example, in the system of care model, case management becomes the primary modality for management of service utilization, rather than arbitrary, a priori management of benefits. The client-centered case management approach, combined with the principle of least restrictive level of care, results in children actually receiving higher quality services (with less disruption to their lives and development), and at a lower cost, than when higher, more restrictive levels of care are utilized. However, the nationwide impact on children's mental health systems of care by nationwide managed Medicaid reforms is quite mixed. Some programs resulting in decreased services to high-risk populations, decreased collab-

oration across social agencies, and cost shifting to other service sectors, while others have developed model intensive community-based programs with defined capitation and cost savings (Pumariega, et al., 1997; Winters, Marx, and Pumariega, 2003).

Children in the child welfare system have extremely high mental health needs, with prevalence rates estimated at about 50 percent, yet are significantly undeserved with respect to mental health services. This is understandable considering the enormous stresses these children experience. Already traumatized by the abuse and neglect conditions that led to removal from their parents' care, children placed in foster care are confronted with the additional traumas of the loss of their parents, multiple relocations, uncertainty about their future, and the difficult task of establishing positive attachments to new parent figures and foster siblings. In addition to having symptoms related to trauma and disrupted attachments, they are also at high risk for disruptive behaviors. They have greater difficulties in functioning at home, school, and in their communities, placing them at high risk for additional failed placements and need for residential treatment. Ninety percent of children in foster care are returned to their biological parents and mental health services needed to support the reunification process are often inadequate. Serving children in foster care involves collaboration amongst multiple stakeholders, including the foster parent(s), child welfare worker, mental health professionals, court appointed advocates (or attorney) for the child, possibly the biological parent(s), and/or extended family. Another serious phenomenon is that of families giving up custody of their children as a way to access intensive mental health services for children with inadequate insurance benefits. Children in state custody and at risk are ideal candidates for the system of care approach, which prevents out-of-home placement, supports the strengths of the child and family, and uses natural community supports. Wraparound programs, intensive case management programs, and therapeutic foster care have demonstrated effectiveness with this population of children and families (Marx, Benoit, & Kamradt, 2003).

A number of studies have documented high rates of serious emotional disturbance amongst youth in the juvenile justice system, with estimates of approximately 50-70 percent (Atkins, et al., 1999; Teplin et al., 2002). Youth are referred to juvenile justice due to their propensity to display aggressive or disruptive behaviors, and after multiple disciplinary interventions in schools and out of home placements. They have similar histories as described above for youth in child welfare, and were often previously served by that system. However, these youth typically have underutilized mental health services over their lifetime when compared to cohorts in other systems (Pumariega, et al., 1999). There is also disproportionate representation of minorities in the population of youth served by juvenile justice, especially of African-Americans and Latinos. The juvenile justice and mental health systems have significant differences in their service orientations and philosophies, with the former torn between orientations to punishment versus rehabilitation, while the latter is treatment-oriented. However, areas of natural collaboration between these systems are in the prevention of entry into juvenile justice, particularly into detention/ incarceration, and the treatment of youth with SED into the juvenile justice system. Multisystemic therapy (MST) has been tested extensively with youth at-risk of detention and incarceration, and has resulted in significant reductions in out-of-home placement, externalizing criminal behaviors, rates of arrest and incarceration, and treatment costs (Henggeler et al., 2002). The significant reduction of youth incarceration in the CMHS system of care sites supports the value of community-based systems of care in addressing the needs of this population (Holden et al., 2003).

The educational system faces the impact of the increasing needs of children with learning disorders and serious emotional disturbances, in the context of the underfunding of school districts. A positive development in the area of interagency systems of care is the renewed interest in school-based services. These go beyond traditional school mental health consultation and involve the co-location of health and mental health professionals within schools to provide a wide array of direct and indirect/ preventive health and mental health services. School-based mental health services serve as an as ideal core service for a children's system of care, providing an excellent accessible portal of entry which is non-stigmatizing, and a naturalistic setting to observe behavior and integrate interventions into child's environment. These services are often funded through blended Medicaid fee-for-service and managed care funding augmenting limited school funding. A number of models have been implemented in communities such as Baltimore, Maryland, rural South Carolina, and Charlotte, North Carolina, with documented success in reducing adverse morbidity and increasing access to needed services (Porter, et al., 2003). An innovative approach that mandates interagency collaboration in the development and implementation of individualized educational plans when these involve areas outside of educational services has been implemented in California (Schacht & Hansen, 1999).

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