

Children's Mental Health Services: Policy Implications of the New Paradigm

The Policy Institute for Family Impact Seminars



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Children's Mental Health Services: Policy Implications of the New Paradigm

Background Briefing Report
by Shelley Hara and Theodora Ooms

and highlights of the Seminar held on November 18, 1994,
at 210 Cannon House Office Building, Washington, DC

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Children's Mental Health Services: Policy Implications of the New Paradigm

Introduction	1
Part I. Background	3
Family Vignettes	
Needs, Causes, and Effects	
Causes of Child Mental/Emotional Problems	
Effects on Families	
Effects on Other Child-Serving Systems	
The Traditional Services Paradigm	
Child Mental Health Treatment and Its Effectiveness	
Mental Health Treatment Settings and Their Effectiveness	
Mental Health Service Providers	
Financing Mental Health Treatment	
The Impetus for Reform	
Part II. Emergence of the New Service Paradigm	15
The Underlying Philosophy and Assumptions of the New Paradigm	
Key Components of the New Services Paradigm	
Systems of Care	
The System Infrastructure	
Part III. Evolving New Systems of Care in the Public Sector	21
Federal Initiatives	
Foundation Initiatives	
Examples of Local Systems of Care Initiatives	
State-Level Initiatives	
Common Features	
Research on the New Paradigm	
Part IV. Implications and Challenges for Policy	29
Financing Child Mental Health Services in an Era. of Managed Care	
Human Resource Development and Staffing Needs	
Coordination with Other Child and Family Serving Systems	

Organizational Resources	33
Selected References	37
Highlights of the Seminar.....	41
Chart I. Changing Mental Health Services Assumptions.....	51
Chart II. Values and Principles for the System of Care.....	52
Chart III. Components of the System of Care.....	53
Chart IV. Dimension I: Mental Health Services	54

Children's Mental Health Services: Policy Implications of the New Paradigm

A Background Briefing Report
by Shelly Hara and Theodora Ooms

Introduction

For too long, children's mental health has been the Cinderella of child and family services—an underfunded, low priority at both the state and federal levels. In spite of numerous studies and reports documenting many unmet needs, there are no federal commitment to provide for the needs of the estimated eight percent of all children who have serious emotional and mental disorders and their families, nor the additional 10-12 percent who have significant problems. In 1982, Jane Knitzer's landmark report noted that these "unclaimed children" were no system's responsibility but every system's problem.

Over the past decade, these children and their families have become somewhat more visible, and their needs better understood. Many in the mental health field became convinced that the effectiveness and efficiency of child mental health services could only be improved if services were radically reformed. A new services paradigm has evolved that guides the reform movement. It requires major changes in patterns of financing, organization and delivery of services, and personnel training. Importantly, it also requires major shifts in thinking about the roles of family members and of mental health professionals.

Stimulated by a small, but strategically focused, federal program, the Child and Adolescent Service System Program (CASSP), state agencies have been striving to develop improved, community-based systems of care that redirect resources away from high-cost institutional care and into community-based alternatives. (CASSP was recently renamed the Planning and System Development Program, but for simplicity's sake will be referred to by its original name in this report.) These developments in child mental health services have recently attracted wider attention at the federal level due, in part, to highly effective public education and advocacy conducted during the 1993-94 debates on health care reform. But many federal agencies are also coming to the growing realization that their current response to the mental health needs of the children and families is ineffective, inefficient, and putting pressure on their budgets. In addition, child welfare, special education, juvenile justice, and other agencies realize that the goals and principles of child mental health service reform have much in common with service innovations and reforms being promoted within their own systems. At local and state levels, these systems are making serious efforts to coordinate and collaborate. At the federal level, a few small steps have been taken, but a great deal more needs to be done.

This *Background Briefing Report* provides, in Part I, the background information needed to understand the rationale for reforming the present systems of child mental health services. Part II outlines the assumptions, principles, and components of the new services paradigm. Part III describes

and provides a few examples of systems reform initiatives sponsored by both the public and private sectors and summarizes some of the positive results these reforms are achieving. Part IV discusses the implications for federal and state policymakers. We argue that major issues and challenges in three important areas need to be addressed if these systems reforms are to fulfill their promise of improving the lives of children with emotional and behavioral disorders and their families.

I. Background

Family Vignettes

We begin with three vignettes of families in need of mental health services. The following examples are taken from Knitzer's report, *Unclaimed Children* (1982).

Sara is seven years old. As a toddler, she was identified as psychotic. She could not follow directions, dress or feed herself, had no language, and often screamed uncontrollably. Fortunately, Sara was enrolled in a special home training program. After intensive work it became clear that she was not psychotic but severely language impaired. After a year in the program, she was enrolled in a special kindergarten class. Now she attends a regular first grade class, although the program she was enrolled in has since been "defunded."

Pablo is an adolescent whose father died young. Pablo's stepfather, with whom he is very close, was recently disabled. Now Pablo has begun to fight with other children and is increasingly fresh to his teachers. School personnel say he is a "discipline problem." At home he is often depressed, cries easily, and is easily angered. He lives in a city rich in psychiatric resources. But he speaks primarily Spanish, and a search for a Spanish-speaking male therapist has proved futile. An educational advocate trying to help Pablo said bitterly, "no one sees them until they learn English."

Mrs. Carlton, a single parent who is unemployed and on welfare, is the mother of five-year-old twins. One twin was doing well; the other was having severe problems. She frequently refused to eat, had temper tantrums, and woke up sobbing several times a night. Mrs. Carlton sought help from her caseworker, who suggested the children be evaluated. The startling recommendation was that Mrs. Carlton place the troubled child in foster care. Feeling desperate and with nowhere to turn, the mother requested placement. She had no framework for evaluating such "expert" advice. Fortunately, she became increasingly anxious about what she had done and before two weeks went by she approached legal services for help. Her lawyer helped her get her traumatized child out of placement and to an excellent child mental health clinic where the family began to receive therapy.

Need, Causes, and Effects

(Sources: Brandenburg, et al., 1990; Costello, et al., 1993; Friedman, forthcoming; Knitzer, 1982; Knitzer, et al., 1990; Pires, 1991; U.S. Congress, 1986)

There seems to be general agreement among mental health experts that the majority of children who need mental health services do not receive them, and, for those that do, many of the services are inappropriate. There is also evidence that the proportion of children needing mental health services is rising. But how is the concept of "need" defined and assessed?

Prevalence. Based on medical diagnostic criteria, most prevalence estimates attempt to assess the rates of mental health disorders in the child and adolescent population. Past estimates have varied

considerably depending on the definitions and methods that are used. Nevertheless, recent reviews of these studies conclude that there has been a remarkable (and disturbing) consistency in the findings: somewhere in the region of 14-20 percent of children have at least one mental disorder. Of these, about half (between 8-12 percent of the child population) have significant impairment in their functioning at home, in school, or with peers. Earlier reports have found that between 3-8 percent of children are severely, emotionally disturbed (see Knitzer, 1982, and U.S. Congress, 1986).

The mental health field lacks consensus about who can be defined as emotionally disturbed, who is defined as “normal”, and who is in need of mental health services. Are all children with a diagnosable “disorder” in need of services, or only those who have a disorder *and* show serious impairments in functioning? Or, is it also all those who are “at risk” of developing a disorder? Over the years, the definitions of those in need have expanded considerably.

Trends. In general, few data are available to establish trends in prevalence rates over time. However, recent studies suggest that there is a growing proportion of children who exhibit serious emotional/behavioral problems as exemplified by the rise in young, white male suicide rates and in young, black male homicides. This rise is not simply a reflection of better reporting rates and less stigma attached to mental illness, but is a consequence of many troubling trends in society, such as increasing poverty, parental psychopathology (depression, schizophrenia, substance abuse), family instability, homelessness, community deterioration, and so forth (see Friedman, forthcoming).

Clinical definitions. For purposes of obtaining third-party reimbursement, mental health professionals usually use the definitional criteria laid out in the basic source book, the American Psychiatric Association’s *Diagnostic Statistical Manual*. The latest revised edition, the DSM-IV, was published in 1993. The DSM classification scheme for children includes a wide range of “disorders.” It outlines five basic dimensions of disorders that typically arise in childhood, and within each there is a range of severity. This classification scheme is also the framework for research and teaching in the university training programs. The five dimensions are:

- intellectual (mental retardation),
- developmental (e.g., autism and dyslexia),
- behavioral (e.g., attention problems like attention deficit disorder, hyperactivity disorder, and conduct disorders, including stealing, fighting, or temper tantrums),
- emotional (e.g., separation anxiety), and
- physical (psycho-physiological, such as eating disorders, stuttering, bedwetting, and sleeping problems).

In addition, the diagnostic categories include child and adolescent versions of disorders that are most commonly experienced in adulthood, such as depression, schizophrenia, phobia, and substance abuse.

In the DSM-IV classification scheme, a clinician making an assessment of a child will assign a specific diagnosis and rate it in terms of severity and level of functioning. Since it is quite common for a child to experience two or three disorders at a time, the clinician will usually need to select one as the primary disorder (dual/triple diagnoses are also permitted). The DSM diagnostic criteria must be assigned to the child patient in order to obtain third-party payment. As Knitzer (1982) noted, many clinicians, service providers, and parents feel conflicted about the requirement to label a child as having an emotional disorder (illness) in order to obtain help. While some diagnoses may suggest

a course of treatment, typically the diagnosis does not serve as a guide for what kind of intervention is needed in any particular case. Some parents may welcome a diagnosis as the entry into needed services. However, others will resent the fact that their child is given a stigmatizing label, especially when the behaviors causing the parents concern are common and temporary in nature. Professionals object to having to label the child when the child's behavior or symptom is basically a reaction to a dysfunctional home, community, or school setting.

Some researchers have pointed out that the DSM diagnostic process has very low reliability for the major child diagnostic categories. As a result, they recommend using behavioral classifications that are more reliably assessed and less stigmatizing, such as replacing *serious emotional disturbance* with *severely maladjusted behavior* (Burchard & Clarke, 1990). A coalition of mental health and special education national organizations has recently proposed an alternative definition suggesting SED children should be described as “children with emotional or behavioral disorders.”

In late 1994, Zero to Three/National Center for Clinical Infant Programs published the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood*, a comprehensive framework for diagnosing emotional and developmental problems in the first three years of life. The product of a multi-disciplinary task force, this tool seeks to fill the gap in the ability to diagnose, prevent, and treat difficulties in the earliest years by identifying and describing disorders not addressed in other classification systems and the earliest manifestations of problems described in other systems for older children and adults.

Public policy definitions. For public policy purposes, the population of children in need of mental health services is usually broken down into three categories according to the degree of severity of impairment in functioning:

1. Seriously mentally ill—these typically include children with certain DSM diagnoses, which the National Association of the Mentally Ill (NAMI) believes have their basis in neuro-biological brain disease (NBD).
2. Seriously Emotionally Disturbed (SED)—a term used in the federal Child and Adolescent Service System Program (CASSP) and community mental health legislation (see below).
3. Children “at risk” of developing an emotional/mental disorder.

The federal CASSP program (see p. 21) provides grants to states to improve service systems for Seriously Emotionally Disturbed (SED) children and their families. The CASSP guidelines regarding who is eligible are relatively broad and essentially define SED in functional terms: children who have had a diagnosable DSM-III-R disorder that has persisted for at least one year and that requires the services of two or more community agencies. Recent proposals to modify this definition somewhat brought forth a storm of comment. The controversy over the definitions used in this and other programs clearly reflect competition for scarce mental health resources among the different advocacy groups rather than a serious disagreement about which children and families need services.

State mental health agencies, required to develop plans for their community-based service systems for SED adults and children, have chosen to adopt varied definitions of the population of children in need of mental health services. Within these definitions, they select the categories that have priorities for services. Increasingly, states are choosing to define groups of children who are “at risk” for emotional disturbance as targets for mental health services (Pires, 1991).

It is important to note that different child-serving systems may use different terms to label a child exhibiting a particular pattern of behavior. For example, the juvenile justice system may call a child an “incorrigible” child or a Person in Need of Supervision (PIN), while the child welfare system labels the same child as “abused and neglected.” The mental health system might label the same child as having an “adjustment reaction disorder” or “oppositional defiance disorder.”

As Knitzer (1982) and many others have noted, it is often arbitrary which service system “door” a child enters. Furthermore, many studies have shown that minority children, who are less likely to receive mental health services, are more likely to be labeled as in need of special education placement or the correctional system than white children exhibiting the same problems.

Causes of Child Mental/Emotional Problems

(Sources: Combrinck-Graham, 1990; Institute of Medicine, 1989; NAMHC, 1990; U.S. Congress, 1986)

There is broad agreement in the mental health community that biological, psychological, relational, and environmental factors all contribute to the development and maintenance of children’s emotional, intellectual, and behavioral problems. For any one child, a single causal factor may be dominant, but typically several factors are involved and are interrelated. For example, a child with a genetic predisposition to mental illness will be more vulnerable to environmental stress or discord in the family, and to traumatic life events or illness. Similarly, a child with an intellectual disorder (e.g., Downs Syndrome), when reared in a positive family environment, may function better at home than in an institution.

It should be mentioned, however, that there is an influential group of parents from the National Alliance for the Mentally Ill (NAMI) that strongly believes that the primary causes of severe mental illness are biological. They are strong advocates for more research and treatment that is focused on neuro-biologically based brain disease.

The clinical model of etiology—understanding the causes in order to prescribe treatment of illness and disease—is being modified and expanded through the addition of public health concepts of risk and protective factors. These concepts emphasize preventive intervention in addition to treatment.

Environmental risk factors. As interest grows in devoting more resources to mental health prevention, there is increasing attention placed on identifying those environmental factors that place children “at risk” for developing emotional and behavioral problems. A 1986 Office of Technology Assessment (OTA) report lists the primary risk factors identified in the research but emphasized that it was only when a child was exposed to several factors at once that the “risk” became most salient. The risk factors included poverty, combined with minority status; parental psychopathology (depression, schizophrenia, alcoholism); parental abuse and neglect; parental conflict and divorce; teenage parenthood (which places both the child and the teen at risk); premature birth and low birthweight; and major/chronic physical illness. The 1990 report of the National Advisory Mental Health Council added to this list these factors: genetic factors that predispose a child to the development of an emotional disorder (for example, learning disorders); cognitive impairments; and biological insults such as exposure to toxic chemicals or drugs (NAMHC, 1990). More recent studies have focused on additional environmental factors, such as exposure to violence and homelessness.

Protective factors. Research emphasizes that children at risk of developing mental disorders may also be exposed to various protective factors, which serve to prevent these disorders from occurring or ameliorate their severity. Until recently, there has been less research on what these protective factors are. But the emerging resiliency and prevention literature suggests that a child can develop quite well under adverse family circumstances - for example, living with a severely mentally ill parent, especially if the other parent or some other close relative has a good, stable relationship with the child.

Effects on Families

(Sources: Chesapeake Institute, 1994; Knitzer, 1982)

Caring for children is demanding for most families, but caring for a severely emotionally disturbed child creates extraordinary demands and challenges that can be highly stressful and interfere with a family's normal functioning. For example, at times such a child may require 24-hour supervision and behavior management. The family caregiver may find it extremely difficult to go to the grocery store, work regularly, attend school functions, and address the needs of the other children and family members. Meeting such a child's needs can also interfere with maintaining an intimate relationship with a spouse.

The task of caring for an SED child is difficult enough when there are two parents in the household, but, increasingly, children are being cared for by a single parent. Unless there is strong support available from extended kin or close friends, a single parent may find the responsibility overwhelming.

Children with violent, uncontrolled outbursts can dramatically disrupt family life and, even worse, may pose a serious threat to themselves or others in the family. When the behavior persists, and there is the prospect of the child becoming a long-term dependent of the family through adolescence and into adulthood, family members typically experience feelings of anger, guilt, and depression.

Families often have nightmarish experiences trying to obtain the services they need for their emotionally disturbed child. They visit professional after professional, are shuffled from system to system, feeling always in a one-down position. Too often, their concerns are ignored, and/or they are blamed for their child's difficulties. If they are fortunate enough to find some services that are truly helpful—and have the insurance coverage and resources to pay for them—they then have the burden and responsibility to function as the de facto case manager without the authority to make many of the decisions involved.

Effects on Other Child-Serving Systems

Children experiencing serious mental health problems typically have difficulties in school with learning and with relationships with classmates and school personnel. Schools, under the mandate of the Individuals with Disabilities Education Act, should provide a variety of educational and psychological/counseling services, in addition to special education classes, for children with severe emotional disorders. However, this has been problematic as school-related outcomes for this population are poor (Knitzer, 1992; Chesapeake Institute, 1994). But with the increasingly strong federal mandates to provide appropriate services for children with disabilities in the least restrictive

setting, teachers are frequently required to include children with severe emotional disorders in the regular classroom. They often feel they have neither the resources nor the special training necessary. Both educators and parents are concerned that one of the consequences is that the other “normal” children are not getting their share of the teacher’s time and attention.

Many children who have emotional/behavioral problems, especially those from low-income/minority backgrounds, end up being served in the child welfare system and juvenile justice system. These systems typically have few, if any, mental health services to offer, and the foster parents and residential program staff are not trained to respond to their needs. Moreover, the children’s difficulties may be intensified by the trauma of separation from their homes, and repeated changes in foster care or residential placements can make their emotional and behavior problems worse. Consequently, this pressure on the system may result in longer, more costly, treatment services.

The Traditional Services Paradigm

(Sources: Knitzer, 1982; Lourie & Katz-Leavy, 1991; Stroul, et al., 1994; U.S. Congress, 1986)

In this report, we reflect current thinking in the field of child mental health and make a distinction between the traditional and the new service paradigms. By paradigm, we refer to both a set of conceptual assumptions and principles and the way in which these assumptions are operationalized in terms of specific services. The assumptions and principles of the new paradigm have been clearly spelled out in a few seminal documents and discussed extensively (see p. 15). In contrast, it is not possible to point to one or two documents that outline the assumptions of the traditional paradigm. Given the great variety of psychological theories, therapeutic approaches, and patterns of services, it may seem simplistic to identify a single traditional paradigm.

Nevertheless, we believe it will be useful to tease out a few of the basic assumptions that underlie the current patterns of organization and financing of the existing mental health services in both the public and private sector. We then briefly describe the elements of these services to help understand what is new about the “new paradigm” of mental health services.

The system of child mental health services that has evolved over the past fifty years has its roots in the community-based child guidance movement that flourished in several major communities in the 1920s and 1930s. This movement was influenced by the parent education movement and juvenile court-related social work. However, children’s mental health services have since been integrated into the adult mental health system, which, in recent decades, has essentially been governed by the “medical” model. This model incorporates two somewhat distinct treatment philosophies - the psychodynamic view and the behavioral view (see Knitzer, 1982: 16). Chart I contrasts the assumptions of the traditional “disease” paradigm with those of the new “systems” paradigm.

Child Mental Health Treatment and Its Effectiveness

(Sources: Snyder & Ooms, 1992; U.S. Congress, 1986)

How are the underlying assumptions of the traditional paradigm operationalized? What kinds of mental health treatment are generally provided to children in the public and private sectors and how effective are they?

The 1986 OTA report provides a useful description of the predominant types of therapy available and the different settings in which children receive them. The principal child treatment methods currently used by mental health professionals are

- individual therapy,
- group and family therapy,
- milieu (total environment) therapy,
- crisis intervention, and
- psychopharmacological (drug) therapy.

Within each of these categories of therapy, the report distinguishes different schools of theory and practice. It notes, however, that

The paradigm for mental health treatment has traditionally been individual therapy—the one-to-one encounter of a therapist and a patient. Over the past 50 years, there have developed a large number of individually based therapies based on theories as disparate as psychoanalysis and operant conditioning. Each theory has spawned various approaches to individual therapy that have been adapted for use with children ... including psychodynamic therapy ... behavioral therapy ... and cognitive therapy. (U.S. Congress, 1986: 67)

The OTA report includes a wide-ranging review of the research on the effectiveness of different therapies and notes that there are many gaps and serious methodological problems with these studies, some of which are inherent in the nature of the treatment. However, its “fundamental conclusion is that professional mental health treatment leads to significantly better outcomes than no treatment.” Some studies have found that certain types of therapy appear to be effective with specific types of disorders, such as the effectiveness of structural family therapy with psychosomatic disorders (anorexia and chronic, severe asthma), functional family therapy with delinquent adolescents, and behavioral therapy with phobias and bed-wetting. In general, this field of research is in its infancy.

Mental Health Treatment Settings and Their Effectiveness

(Sources: Burns & Friedman, 1990; U.S. Congress, 1986)

The traditional settings in which mental health treatment is provided to children range in intensity and length of stay. Settings include hospitals, residential treatment centers (RTCs), day treatment programs, and outpatient settings, such as community mental health centers or private clinics or therapists offices. A child/adolescent psychiatric inpatient facility may be a unit within an adult mental hospital or a general hospital, or it may be freestanding. Some offer treatment for substance abuse/chemical dependency, although substance abuse inpatient/residential services are typically separate from mental health inpatient units. Inpatient services are much more costly than community-based services. Day treatment, called partial hospitalization in certain communities, is also provide in different settings. It may be part of a hospital or residential treatment program or it may be freestanding or connected to a school day treatment program. Partial hospitalization generally provides services to youngsters for a minimum of six hours per day.

While this range of treatment services may exist in theory, they are clearly not evident in every community. Report after report has documented that in most communities the only mental health

treatment available for children and their families is once-a-week outpatient therapy and inpatient/residential services. In many states, there is such a serious shortage of residential treatment services or alternative community-based nonresidential programs that children are placed far away from their homes, often in another state.

The OTA review reports that the current state of intervention research makes it very difficult to draw conclusions about effectiveness of settings, since it is generally not possible to separate outcomes due to particular treatment modalities (therapies) from those due to particular settings. Experimental studies and clinical trials using control groups or comparison groups of children are not generally used, which makes it difficult to compare the relative effects of different settings in treating similar problems.

The most extensive efficacy research has been conducted on outpatient psychotherapy. Recent reviews report significant gains, which vary somewhat with the type of psychotherapy used, the age of the child, and the disorder. One fairly consistent finding is that although most children treated at RTCs do improve during treatment, their long-term outcomes depend on the involvement of the family in treatment as well as the amount of stress and/or follow-up support available upon returning home.

A surprising finding—which has important policy relevance—is that, in general, “it appears that the least amount of mental health services research has been done on the most restrictive and most heavily reimbursed treatment settings, namely hospitals and residential treatment centers” (Burns and Friedman, 1990: 92). In a review of studies on child psychiatric hospitalization, the authors were able to find no efficacy research base, very little program evaluations, and just one clinical trial whose findings are outdated. They conclude that “the [recent] growth in inpatient psychiatric hospitalization is occurring in the absence of research support for its effectiveness” (95).

Mental Health Service Providers

(Source: Lourie & Katz-Leavy, 1991)

Therapeutic services, provided in these different settings, are administered by the:

- **Public sector.** The public sector is available primarily through community mental health centers and state hospital programs, but also in schools and other social agencies. This sector serves eligible, low-income children and children with severe problems whose families’ private insurance coverage or personal resources run out.
- **Private nonprofit sector.** This sector offers some outpatient services, but also specializes in providing specialized group living services. This sector serves both clients who can pay themselves (through insurance or on a fee-for-service basis) and children who are paid for with public funds through contracts or reimbursement.
- **Private for-profit sector.** Over the past decade, this sector has set up a growing number of psychiatric hospitals and RTCs serving children and adolescents. Payments are made through private insurance or by public sector funds.
- **Private practice sector.** The private practice sector consists of mental health professionals from the five disciplines who sell their services to anyone who can afford them. Many private practitioners offer fees on a sliding scale basis and accept public payments.

Five categories of professionals are designated by the Department of Health and Human Services as qualified mental health professionals: psychiatrists, psychologists, social workers, psychiatric nurses, and marriage and family therapists.

Each category of professionals has to meet state licensing requirements in order to practice and to obtain financial reimbursement from third-party payors. In some cases (for example, for family therapists and social workers), the third-party payor may only reimburse the clinician for treatment if it is provided under medical supervision. In inpatient day treatment and residential settings, many other types of professionals and paraprofessionals may be considered as part of the treatment teams.

Financing Mental Health Treatment

(Sources: Fox et al., 1991; Knitzer, 1982; Lynch, 1992; Schiedemandel, 1989; Stroul, et al., 1994; U.S. Congress, 1986; Weithom, 1988)

Under the traditional paradigm, financing of children's mental health services is provided for eligible, low-income children through state and federal reimbursement programs and for others through private third party payors. The common thread in both public and private sectors is that payment is nearly always based on a fee for service for children with diagnosed mental disorders. This fact, in addition to the limitations on available benefits, seriously limit the type and length of services covered, especially those provided in the community. For example, current financing patterns pose serious barriers to coverage of psychoeducational services, family therapy, consultation with teachers, respite care for families, or other community-based services.

As often noted in the recent health care reform debates, there are large numbers of families who have no medical insurance for their children or whose insurance does not provide any mental health coverage at all. Mental health treatment (for all ages) is financed primarily by State Mental Health Agencies (SMHAs). The CDF/Knitzer study reported that an estimated two-thirds of children in need of mental health services do not receive them, although lack of insurance coverage or ineligibility for public aid is only one of a number of causes for underutilization.

Public sector. The primary sources of federal financing for children's mental health services are:

- **The Community Mental Health Services Block Grant**, created in 1981, consolidated a number of mental health categorical programs and the Community Mental Health Centers and Mental Health Systems Act. While the community mental health centers were required to provide specialized outpatient services for children, it was not until the 1985 amendments that there was a requirement that 10% of the mental health block grant be set aside by states for new programs for children and other underserved areas and populations. With loose reporting requirements for the block grants, it is not possible to keep track of how much is spent on children.
- **The Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)** provides reimbursement for outpatient and inpatient mental health services for child dependents of active, retired, or deceased members of the armed services. In 1985, CHAMPUS spent 60% of its mental health expenditures on treatment for children. Because the mental health and substance abuse benefits are generous, and perhaps in part due to lack of an intensive array of community-based mental health services for children in many of the communities where military families reside, the

numbers of children served in psychiatric inpatient units and RTCs escalated greatly in the 1980s. This rise resulted in recent attempts to place increased limits on lengths of stay to control costs.

- **Medicaid** is financed and administered jointly by federal and state governments. States, however, have considerable authority to shape the program; in addition to a core of federally required benefits, other benefits may be covered at state option. Within broad guidelines, states are free to establish the amount, duration, and scope of services they will cover under a benefit category. They may also impose prior authorization or other utilization requirements (Fox, et al., 1991). In effect, then, Medicaid is fifty different programs.

In the Medicaid program, states are required to provide a range of mental health/substance abuse services (outpatient and inpatient hospital services, physician services, and EPSDT) to children from eligible families. Children are eligible in three ways: by categorical eligibility (AFDC and SSI), as low-income recipients not linked to a cash assistance program (varies by state), and as medically needy (an optional program operated by 36 states). In about half the states, outpatient and inpatient mental health services are provided without limits on coverage. In recent years, a few states have chosen to use Medicaid dollars to cover a wider range of community-based services, including intensive case management for designated populations.

- The **Medicaid Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT)** is a mandatory benefit under the Medicaid program that provides screening and diagnostic services to detect physical or mental defects as well as services to furnish appropriate treatment for any identified disorders. States are required to provide any service identified as necessary to meet the child's assessed need regardless of whether it is included in the state Medicaid Plan, as long as it is an allowable Medicaid service. Unlike most other programs, it provides coverage of referral, transportation, and follow up services to ensure that treatment is provided. In general, this program is regarded as a greatly underused source of financing for mental health and substance abuse services for children (see Fox et al., 1991).
- The **Child and Adolescent Service System Program** is described below. This federal program, established in 1984, does not directly fund child mental health services, but provides grants to states to help them build the infrastructure necessary to provide a more comprehensive and cohesive system of community-based services.
- The **Comprehensive Community Mental Health Services for Children Program**, enacted in 1992, currently provides grants to states, political subdivisions within states, and Indian Tribes to establish model systems of care in targeted communities. This program requires the communities to put into place an array of community-based services.
- Federal programs administered under other departments and agencies can also help states fund child mental health services, such as the Individuals with Disabilities Education Act (IDEA), maternal and child health block grants, programs for the developmentally disabled, child welfare programs, and so forth.

Private sector. When families have private medical insurance, the coverage for child mental health services is generally more limited than what is permissible under the Medicaid program. Copayments and dollar limits per year or per visit are typical, as are limits on the number of visits per year. While most insurance programs provide some coverage for inpatient psychiatric care, coverage is more limited than it

is for hospitalization for a physical illness. Private insurance typically does not cover intermediate services, such as day treatment, case management, in-home services, and therapeutic day care.

Based on Bureau of Labor Statistics Employers data, a survey of insurance coverage for psychiatric illness in the private sector was conducted by the American Psychiatric Association. The survey revealed that insurance coverage for alcohol and drug abuse increased dramatically during the 1980s, whereas outpatient coverage for treatment of mental illness probably deteriorated (Schiedemandel, 1989).

Outpatient benefits are often limited to brief visits to a psychiatrist. Any coverage of psychotherapy provided by licensed mental health professionals requires extremely high copayments (50% or more) and is limited to only a number of sessions per year. Although clinical psychologists, social workers, and psychiatric nurses are generally reimbursed, many managed care/insurance plans do not reimburse for services provided by family therapists even though they are recognized as qualified mental health professionals. And family therapy is seldom a reimbursable service. In addition, insurers may deny mental health coverage to families when one member of the family has already used mental health services.

The result of these patterns of third-party reimbursement is that too often children are placed inappropriately in inpatient treatment, and the limited coverage frequently results in cost shifting to the public sector. When their children have serious and persistent problems, parents quickly run out of insurance and have to apply to public programs for assistance. In a number of states, this has resulted in the parents having to relinquish custody to the state child welfare agency in order to be eligible for the services they need for their children. Only 29 states have provisions for voluntary placement whereby parents can retain full custody.

The benefit structures of private insurance have typically encouraged the development of excess capacity in institutional care and discouraged the development of alternative community-based services.

The Impetus for Reform

(Sources: Cole & Poe, 1993; Knitzer, 1982; Knitzer, 1993; Knitter, Steinberg, & Fleisch, 1990; Lourie & Katz-Leavy, 1991; Stroul & Friedman, 1986; U.S. Congress, 1986)

Beginning with the 1969 report of the Joint Commission on the Mental Health of Children, *Crisis in Child Mental Health: Challenges for the 1970s*, a series of national studies and commissions have pointed out the unmet needs and serious problems with existing child mental health services. In response to these reports, landmark federal legislation in 1984 and 1992, while modest in terms of funding levels, has helped to dramatically reform the way child mental health services are conceptualized, designed, and delivered.

Initially, the principal conclusion of several of these reports was that the crisis in child mental health “revolves around perceptions regarding an enormous need for services, insufficient personnel to meet the need, increasing risks to children, a prevalent pathology in our society, and inadequate resources” (Combrinck-Graham, 1990: 10). The logical conclusion was that the solution to the crisis was to fund more mental health personnel to provide more services.

In 1982, Jane Knitzer authored the Children’s Defense Fund report, *Unclaimed Children*, which proposed a bold new direction for reform. Knitzer’s report summarized the findings of a survey

of state mental health programs. It proved to be a landmark study not only because of its careful description of current patterns of services, but also because it carefully analyzed and critiqued some of the assumptions of the traditional service paradigm. The study also described many innovative program approaches. The report highlighted four basic problems with the existing state of children's mental health:

- State mental health departments gave low priority to the needs of children and adolescents with emotional and behavioral problems. In half the states, no staff were specifically assigned to have responsibility for children and youth.
- Even when children's mental health problems were a focus, states viewed them in isolation, with little interaction between state mental health agencies and other public agencies that often served the same children.
- A dramatic gap existed between service needs and the services actually provided. Most likely to be unserved or underserved were adolescents, abused and neglected children, children of substance abusing or mentally ill parents, and children from minority backgrounds.
- The pattern of existing services, even if there were more of them, simply could not meet the complex, multiple needs of the children and their families. Too many children were hospitalized or placed in residential treatment because once-a-week outpatient therapy was not deemed sufficient for them, and there were no alternative more intensive treatment services available in the community. Further, in many states, between one-half and one-third of the hospitalized youth were in the custody of child welfare agencies because their families were unable to pay for costly out-of-home treatment. These unnecessary placements created additional stress and trauma for the children and their families and absorbed increasing proportions of the state mental health and child welfare dollars.

Various experts have since elaborated on Knitzer's analysis. Even as current benefit structures limit the array of covered services, they do not limit costs nor encourage the use of the most effective treatment modalities (Stroul, et al., 1994).

Limited insurance coverage of mental health services for children has resulted in cost shifting to public systems that serve children (mental health, child welfare, juvenile justice, education, and health). Because the education, child welfare, and juvenile justice systems have legal mandates to serve children, they bear a disproportionate share of costs of providing mental health services, especially residential services. Yet none of the other child-serving systems has designated mental health funding streams, nor are they structured to be mental health care providers. Often these systems are the only avenue to mental health services for families without adequate insurance coverage. Families must often resort to relinquishing custody to the child welfare system or suing the education system. Knitzer referred to these children and families as "unclaimed" by the public agencies that had the responsibility to serve them.

Building on some of the most innovative thinking and practice in the field, Knitzer's cogent prescription for the kinds of systemic changes needed in the organization and financing of health care was extremely timely. It fueled the call for a radical reexamination of the traditional mental health paradigm.

II. EMERGENCE OF THE NEW SERVICE PARADIGM

The Underlying Philosophy and Assumptions of the New Paradigm

(Sources: Combrinck-Graham, 1990; Lourie & Katz-Leavy, 1991; U.S. Congress, 1986)

In 1984, the widespread attention the *Unclaimed Children* report received, followed by strong advocacy from a coalition of individuals and groups, provided the impetus for Congress to authorize, through the National Institute of Mental Health (NIMH), the Child and Adolescent Service System Program (CASSP). CASSP operationalized a new philosophy and mission for children's mental health services by providing planning grants to states to develop community-based, organized systems of care for youth with serious emotional disturbances.

In 1986, the Office of Technology Assistance (OTA) published the report of its comprehensive study which echoed the crisis in children's mental health services, again citing the failure of the mental health and other public systems to adequately address the needs of children and adolescents with mental health problems. It also pointed out the promise of the new innovations.

Theoretical Shift. Underlying the new proposals for reforming children's mental health services was a shift in the theoretical framework being used to understand children's emotional and behavioral difficulties and prescribe appropriate interventions. The linear, disease concepts were giving way to a focus on context and systems (Combrinck-Graham, 1990). This ecological, systems paradigm builds on biopsychosocial and public health approaches but also adds concepts from other disciplines. Chart I schematically contrasts the assumptions of the traditional medical, "disease" paradigm with the new "systems" paradigm.

Key Components of the New Services Paradigm

(Sources: Combrinck-Graham, 1990; Cole & Poe, 1993; Friesen & Koroloff, 1990; Knitzer, 1993; Lourie & Katz-Leavy, 1991; Stroul & Friedman, 1986; U.S. Congress, 1986)

In the last decade, a broad consensus has emerged around the values, goals, and principles undergirding a new paradigm for children's mental health services. The vision of what needs to be put in place is now clear. The challenge lies in the difficult, complex tasks involved in reforming the present system to implement the new vision.

It is important to note that the new service paradigm in children's mental health has emerged primarily from the experience of innovative demonstrations in the public sector. Child and adolescent mental health services provided in the private sector are still for the most part tied to the traditional model.

Knitzer (1993) recently summarized the key themes of the new paradigm by identifying significant shifts in thinking that have occurred in four areas: new roles for families, intensity of services, cultural sensitivity, and the development of community-based systems of care.

1. New roles for families

(Sources: Friesen & Koroloff, 1990; Knitzer, 1993; Lourie & Katz-Leavy, 1991; Ooms & Preister, 1988; Staton, Ooms, & Owen, 1991; Stroul & Friedman, 1986; Vosler-Hunter, 1989)

In the new service paradigm, the families of children and adolescents with emotional problems are invited to assume new roles at the clinical, program, and policy levels.

First, whereas traditional mental health theory and practice tended to label families as dysfunctional and the source of pathology, in the new paradigm the focus has shifted to identifying the strengths of families, viewing them as a resource and seeing the potential for change when families are involved in the helping process. As experts on their own children, parents have taken on new roles as partners with professionals, participating in the planning and delivery of services for their children.

Second, the family increasingly is seen as the focus of services and intervention, rather than the child in isolation. It is now acknowledged that the family is the primary social institution, and that parents need adequate supports to effectively raise their children. Thus, a new emphasis has emerged on providing a variety of services that help to support parents in carrying out their responsibilities rather than to replace or undermine them. There is also a new appreciation of the importance of the relationship between the parents, extended kin, and both formal and informal supports within the community. This emphasis reflects the more ecological approach to intervention and highlights the importance of family support services—like respite care and family support groups—in addressing the needs of children with mental health problems.

Third, it is now believed that families should also be involved in planning and overseeing services at the system level in order to ensure that new systems meet the needs of children and families. In other words, parents should not only be partners in service delivery for their own children, but should participate in designing and delivering services for other children with emotional disabilities.

CASSP established the goal of family involvement and participation as a major area of emphasis for all of its grantees and has encouraged more activity in this area. Since 1988, CASSP also has provided support for technical assistance to parent groups to assist them in forming statewide parent organizations. The federally funded Portland Research and Training Center's Families as Allies project has focused specifically on strategies for effective parent-professional collaboration. Two national parent organizations have been formed, the Federation of Families for Children's Mental Health and the National Alliance for the Mentally Ill's Child and Adolescent Network (NAMI-CAN). Parents are now serving on mental health boards, advisory committees, boards of directors, and planning councils, where their input is critical to improving systems of care.

2. Rethinking intensity

(Sources: Cole & Poe, 1993; Knitzer, 1993; Ooms & Binder, 1993; Stroul & Friedman, 1986)

In the old paradigm, intensity was generally equated with the level—or restrictiveness—of out-of-home placement. If a child required services more intensive than those provided through traditional, once-a-week, outpatient therapy, the child was most often removed from the home and placed in a structured treatment environment such as a residential treatment center. Because such out-of-home placements were only provided through the child welfare system, parents were often required to give up custody (and termed neglectful) in order to obtain them. In addition, if appropriate treatment was not available in the child's home community, it was not uncommon to place children far away from home, and even out-of-state.

It is now generally believed that intensive services can be provided in natural environments, a principle that is rooted in the family preservation movement and individualized wraparound services. Family preservation services are “time-limited, intensive interventions offered to families facing the crisis of imminent removal of a child from their home for placement” by child welfare, mental health, and sometimes juvenile justice systems (Ooms and Binder, 1993). These services, at least in the short term, help to avoid placement and engage families in the helping process.

Individualized wraparound services have been utilized primarily in the child mental health system and extend the concept beyond short-term, intensive family preservation. Wraparound typically connotes setting aside flexible dollars to pay for nontraditional services, which are often needed to help troubled youth remain in the community and participate in traditional service programs.

Importantly, underlying this change in perspective is the belief or value that children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate. Accordingly, the service system should reduce reliance on restrictive treatment environments and out-of-home placements.

3. Enhancing Cultural Sensitivity

(Sources: Cross, et al., 1989; Focal Point, 1994; Isaacs & Benjamin, 1991; Katz-Leavy, Lourie, & Kaufmann, 1987; Knitzer, 1993)

Two related values or principles have become evident relevant to children of color. First, children with emotional disturbances should receive services without regard to race, religion, national origin, or other characteristics, such as sex or physical disability. In other words, all children in need of mental health services should have access to them. Knitzer (1982, 1993) highlights the fact that children in the mental health system tend to be white, while juvenile justice clients are largely minority. Other data have shown that Black children are overrepresented in the public service sector and in less desirable placements (Cross, et al., 1989). In addition to equal access to services, race or culture should not determine the type of services a child receives.

Secondly, as the general population becomes more diverse and the target population is defined more broadly, the mental health system will serve a larger proportion of minority children in the years to come. CASSP has articulated the value that systems of care should be “culturally competent,” that is, they should consist of agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve. For example, experiences or behavior that may be normative in one culture can be interpreted as pathological in another.

In 1987, CASSP instituted a Minority Initiative to assist states and communities in addressing the goal of culturally competent services. In 1989, the CASSP Technical Assistance Center at Georgetown University’s Child Development Center published *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed* (Cross, et al.). This resource provided a philosophical framework and practical tools for improving service delivery to children of color with serious emotional disturbances. (A subsequent volume, published in 1991, showcased “Programs Which Utilize Culturally Competent Principles.”) The CASSP monograph addresses policy, training, resource, practice, and research issues as they affect the provision of mental health services to minority children and their families.

Some examples of these issues include: accessibility of services for different cultural groups, as related to resources, language, cultural perceptions of mental illness, etc.; professional training issues, such as culturally relevant curricula and recruitment and retention of minority practitioners; policy issues, such as having “mainstream” providers become more culturally competent as well as contracting out services to minority-operated programs; and practice issues, such as culturally biased assessment techniques and culturally appropriate definitions of the family.

4. Community-Based Systems of Care

(Sources: Friedman, 1990; Knitzer, 1993; Stroul & Friedman, 1986)

As noted, the traditional services model was a relatively simple one, consisting primarily of outpatient therapy and inpatient care. That model has been replaced with more complex models as described in Stroul and Friedman’s seminal work, *A System of Care for Children & Youth with Severe Emotional Disturbances* (1986), a publication of the CASSP Technical Assistance Center. This publication clearly articulates the CASSP philosophy and conceptualization of a comprehensive system of care for children with mental health needs. The principles and philosophy of the systems of care model have been highly influential in the development of parallel reforms in the early intervention and child welfare systems. It is important to note that the authors see the model not as a blueprint, but as flexible and evolving.

Systems of Care

The principles that echo these four themes and guide the operationalization of the CASSP model are summarized in Chart II, Values and Principles for the System of Care.

Stroul and Friedman (1986) define a *system of care* as:

a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families.

The coordinated network of services that may be needed to interlink mental health services with other service systems is illustrated in Chart III, Components of the System of Care.

According to Stroul and Friedman, in order for children with emotional and behavioral problems to be served effectively, each community or region should offer a range of nonresidential and residential services. Services should include family support services; mechanisms to ensure that services are linked so children can transition easily from one service to another; the capacity to individualize services; and cross-system collaboration of service planning, treatment, service development, and resource sharing.

Range/array of services. When these new service components are added to the traditional outpatient, inpatient, and residential treatment services, it makes it more feasible to keep the SED child in his/her home and community, thereby fulfilling the philosophical commitment to place the child in the least restrictive environment. Such services include home-based intensive services, 24-hour telephone emergency services, day treatment, and respite care for the parents. If out-of-home placement cannot be avoided, less restrictive placements can be provided with the addition of

services, such as therapeutic foster care and group homes (often administered jointly by child welfare and child mental health). These are illustrated in Chart IV, Dimension I: Mental Health Services.

Individualized, “wraparound” services. This relatively new concept has caused some confusion among mental health professionals who believed they had always placed an emphasis on individualized assessment of their patients’ needs. In fact, with a very restricted range of available services and with funding tied to a restricted list of services, the services an individual child and family needed often could not be provided. The child and family had to fit their needs into the system rather than the other way around. Moreover, the traditional paradigm restricted the vision of the assessment to services provided by mental health professionals. The new ecological assessment opened up possibilities for who could be involved as resources—parents, siblings, neighbors, community residents, and informal organizations—and act as sources of support to SED children and their families.

In the new CASSP model, individualized services can become a reality once a broader spectrum of services is available and a pool of flexible, noncategorical funds is created and then tapped to pay for nontraditional services that can be “wrapped around” the child and family. Such nontraditional services include recreational classes, tutoring, paid big brothers or sisters, transportation, and respite care. This wraparound philosophy requires an unconditional commitment to providing whatever services are needed to the SED child and family. It also requires some creative assessment and inventive planning.

The concept of wraparound services for SED children was originally elaborated in the Kaleidoscope program in Illinois. It was pioneered statewide in the Alaska Youth Initiative where it was used to return children from out-of-state, residential programs. The concept was applied in a more preventive approach in Vermont’s Project Wraparound to prevent children from being removed from their families (Burchard & Clarke, 1990).

The System Infrastructure

(Sources: Duchnowski & Friedman, 1990; Stroul & Friedman, 1986)

In the mental health field, “continuum of care” is used to describe a range of services or program components at varying levels of intensity (Stroul and Friedman, 1986). However, a *system* of care includes not only the services, but the infrastructure needed to create an interlinked system of care, where the different parts are related coherently to each other. Creating a system of care requires that mental health agencies coordinate and collaborate with the major systems serving SED children—principally education, child welfare, juvenile justice, and early intervention—at state, county/administrative, and clinical levels.

At county/administrative levels, various financial, regulatory, and organizational barriers may need to be removed to allow the collaboration necessary for children and their families to be able to access services in a seamless manner. According to Stroul, et al. (1992), in most of the CASSP and other demonstration systems of care initiatives, one or more interagency entities (comprised of agency executives) jointly plans and administers the system of care. This entity assumes responsibility for new policies, joint planning, priority setting, service development, financing, resource allocation, and system management. Formal interagency agreements explicitly define the responsibilities of the various agencies and help sustain the coordination through changes in executive leadership.

At the state levels, the CASSP state program coordinators must assure that the interagency coordination mechanisms critical to enabling the development of community-based systems of care are in place.

At the client/family level, *case management* is the most commonly utilized tool for service coordination. Case management is a term that has wide usage but is used somewhat differently in different program areas (see Ooms, Hara, & Owen, 1992). Early and Poertner (1993) outline the functions of specialized case management in systems of care for SED children and families as (1) assessment, (2) planning, (3) linkage, (4) monitoring, and (5) advocacy. These specialized case managers, who have backgrounds of expertise in working with SED children and families, know how to navigate the various systems involved. Their caseloads are low (15-25), and they may represent (be paid by) child welfare, mental health, or one of the other service systems.

III. EVOLVING NEW SYSTEMS OF CARE IN THE PUBLIC SECTOR

(Sources: Friedman, in press; Knitzer, 1993; Cole & Poe, 1993)

The philosophy, principles, and components of the new system of care paradigm are well articulated in the literature and summarized above in Part II. The next task of this report is to briefly describe where and how the model is being implemented. We will summarize the current status of two key federal initiatives and two private foundation initiatives, and then briefly list a few of the best-known examples of systems of care in development in the public sector. We then review some preliminary results about the effectiveness of these new systems of care.

Federal Initiatives

By the early 1980s, it was clear that the role of the federal government as a funder of child mental health services (never very large) was substantially diminished and not likely to grow in the near future. Therefore, the effort focused on creating a new program designed to build the capacity of states to provide effective services for children with serious emotional disorders and their families. SED children were selected as the priority group, in part because there was a recognition of the tremendous personal and financial costs already incurred by not providing them with appropriate services.

Child and Adolescent Service System Program (CASSP). In 1984, the National Institute of Mental Health (NIMH) began the CASSP program to help states and communities develop the infrastructure to provide comprehensive, coordinated, community-based services to children and adolescents with serious emotional disturbances. (CASSP was recently renamed the Planning and System Development Program, but for simplicity's sake will be referred to by its original name in this report.) The funding was provided to support planning, coordination, and technical assistance activities; known as "glue" money, it served to help existing services become reoriented and work better together.

Originally funded by Congressional appropriations at \$1.5 million, CASSP provided competitive challenge grants to the states to launch activities designed to:

1. enhance leadership for children and youth within state departments of mental health,
2. get state mental health departments to work collaboratively with other state agencies serving children,
3. incorporate new principles of service delivery at the community level,
4. increase family participation in all aspects of the planning and delivery of services,
5. ensure that all systems are able to respond competently to cultural and ethnic differences, and
6. evaluate the progress of states and communities in improving systems of care.

In the first year, NIMH awarded its first competitive CASSP grants of \$150,000 each to ten states. Four years later, all states had received CASSP awards (which can be awarded for up to five years).

The CASSP program is funded at a level of \$12.1 million in FY 1995. In addition to the 29 state infrastructure development grants (in the range of \$130,000-\$200,000), the program also funds a technical assistance arm at Georgetown's Child Development Center (with additional funding from the National Institute of Development and Rehabilitation Research) and two research and training

centers—the Florida Research and Training Center for Children’s Mental Health at the University of South Florida in Tampa, and the Research and Training Center on Family Support and Children’s Mental Health at Portland State University in Oregon (see p. 35). In addition, in FY 1993, CASSP funding provided eight grants for research demonstrations to evaluate the effectiveness of innovative models of organizing, delivering, and financing services, and 28 grants for statewide family networks to improve service systems (around \$50,000 each). While the CASSP program has been small in terms of dollar amounts, the funds have been used strategically. The program has become the catalyst for major changes in thinking and organization of child mental health services.

CASSP is administered by the Child, Adolescent, and Family Branch of the Center for Mental Health Services, Substance Abuse, and Mental Health Services Administration, U.S. Department of Health and Human Services.

Contact: Gary DeCarolis or Velva Spriggs, (301) 443-1333.

The Child Mental Health Services Initiative (Comprehensive Community Mental Health Services for Children Program). Established by legislation in 1992 under the ADAMHA Reorganization Act (P.L. 102-321), the program awards states five-year grants to fund treatment services in communities that have infrastructures to support coordinated and comprehensive service delivery for children, adolescents, and their families. In just two years, the Congressional appropriation has grown from \$5 million to \$60 million (FY 1995).

Currently, 22 sites are funded in 17 states. Compared to the CASSP state grants, the CMHSCP awards are substantial, in the range of \$1 million annually. Hopefully, these funds will permit the site communities to fill in and expand some of the existing gaps in services needed to realize the system of care model.

Under a cooperative agreement with the Center for Mental Health Services, the Washington Business Group on Health has organized a nationwide training and technical assistance network for states and communities receiving children’s service demonstration grants from the Center for Mental Health Services. This initiative, the National Resource Network for Child and Family Mental Health Services, will assist the grantees as they build community-based systems of care that will dramatically improve the quality of services offered to children with serious emotional disturbances and their families. These community-based initiatives are family-centered and closely involve mental health, child welfare, education, juvenile justice, public health, and substance abuse agencies.

The National Resource Network has developed three “Hubs,” which categorize the grantees as small city/county, rural, or urban sites. The hubs provide demographically specific training, consultation, and ongoing technical support to the grantees. Through a multi-agency, family-inclusive process, each community sets its own training agenda and the network tailors its support to fit each community’s needs and priorities. Identified common technical assistance needs will be addressed through multi-state or cross-hub activities. The network will organize and sponsor a consultant resource bank, develop documents and training modules, disseminate hands-on written materials, convene a national best practices forum and coordinate meetings specific to the training and technical assistance needs identified by the sites. In addition, the network has developed a liaison with the Federation of Families for Children’s Mental Health, the Family Leadership Initiative, to ensure that families continue to be full partners in this national initiative.

Like CASSP, this initiative is also administered by the Child, Adolescent, and Family Branch of the Center for Mental Services, SAMHSA, DHHS.

Contact: Gary DeCarolis or Judith Katz-Leavy, (301) 443-1333.

Foundation Initiatives

Mental Health Services Project for Youth (MHSPY). In 1990, the Robert Wood Johnson Foundation awarded a total of \$20.4 million in five-year grants to eight state and community partnerships to demonstrate integrated, effective systems of care (Pennsylvania dropped out after two years). Building on the state-level planning and infrastructure developed through the CASSP program, the MHSPY was the first funded attempt to systematically respond to the complex clinical issues raised by the treatment of children with emotional disturbances through the integrated efforts of all the responsible agencies. It was also the first national children's mental health program with the explicit goal of reforming state and local public policy.

MHSPY demonstration projects are located in the following states: Family Mosaic, California; Bluegrass IMPACT, Kentucky; Children's Initiative, North Carolina; Connections, Ohio; The Partners' Project, Oregon; New Directions, Vermont; and Project FIND, Wisconsin.

The Washington Business Group on Health, Mental Health Services Program for Youth, has been funded by the R.W. Johnson Foundation to provide technical assistance and training to these demonstration sites.

Contact: Ellen Kagen, Mental Health Services Program for Children and Youth, The Washington Business Group on Health, (202) 408-9320.

Mental Health Initiative for Urban Children. In 1992, the Annie E. Casey Foundation launched its Urban Child Mental Health Initiative. This program incorporates an extension of the CASSP framework by attempting to address the needs of all children and families living in high-poverty, inner city neighborhoods. The primary targets are children and families "at risk" as well as SED children. The program aims to build on the resources and strengths of neighborhood-based organizations to provide a range of culturally responsive family support and prevention activities. A unique feature of this initiative is that each funded site is expected to establish neighborhood governance boards or collaboratives that will develop the partnerships needed between local and state governments in order to implement their program and better integrate current services.

In 1992, twelve states were awarded planning grants for this program. In 1993, four states were awarded four-year service development grants for initiatives in small urban neighborhoods in Massachusetts, Florida, Texas, and Virginia.

In addition, the Federation for Families for Child Mental Health is funded by the Casey Foundation to provide technical assistance to these demonstration sites to help develop neighborhood/parent leadership.

Contact: Patrick McCarthy, Annie E. Casey Foundation, 701 St. Paul St., Baltimore, MD 21202, (800) 222-1099.

Examples of Local Systems of Care Initiatives

(Sources: Cole & Poe, 1993; MHSPY, 1993; Stroul, et al., 1992; Stroul & Friedman, 1992)

There are several documents providing summary descriptions of evolving systems of care providing mental health-related services to children and families. We have selected a few of the best-known initiatives that illustrate the range and scope of system development activities currently underway. Over the years, the planning, system development, and coordination activities of these demonstrations have been funded through a variety of sources, including state mental health agencies, foundation grants, and the federal CASSP program. For the most part, the services they provide have been funded through federal and state categorical program dollars and third-party payors.

Ventura County, CA. Formally initiated in 1985 under state law (AB 3920), making it one of the oldest and best-known systems of care, this project has targeted children at risk of out-of-home placement. Using reallocated institutional dollars to provide coordinated, community-based alternatives, a series of interagency structures, agreements, and protocols have successfully diverted children from institutional placements and avoided unnecessary costs while improving treatment effectiveness.

The success of the Ventura model led to state legislation, known as AB 377, creating a permanent structure for continuing Ventura's children's system and providing funds to replicate the model in three other California counties—San Mateo, Santa Cruz, and Riverside. Ultimately, the plan is to implement these systems across the state.

Contact: Randall Feltman, Ventura County, CA, (805) 652-6737

Fort Bragg, NC, Child and Adolescent Mental Health Demonstration Project. The Fort Bragg project serves CHAMPUS-eligible children under age 18 (i.e., military dependents) and their families living in the Fort Bragg area. It provides a continuum of community-based mental health services, applying the principles of managed care. The project was developed and is operated by the North Carolina Department of Human Resources under a cost-reimbursement contract with the Department of the Army, making it a unique federal-state partnership. Many of the services provided are traditionally covered under CHAMPUS benefits, and there are no co-payments, deductibles, or other costs to the families.

Contact: Lenore Behar, PhD, Child and Family Services Branch, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, (919) 733-0598.

Family Mosaic, San Francisco. This project is a Robert Wood Johnson-funded project which serves SED children and their families in the community. San Francisco has one of the most culturally diverse populations in the nation, with at least one-third of its residents having limited or no facility for English. Most of those served by this project are children of color. This neighborhood-based system of care is designed to accomplish a high degree of cultural competence and community cohesion and to utilize culturally diverse staff organized in multi-agency case management teams. Family Mosaic has implemented a prepaid, capitated financing system to permit formerly rigid, discrete services to be flexibly provided in an individualized, culturally sensitive package.

Contact: Charles Morimoto, Director, (415) 206-7600.

State-Level Initiatives

Pennsylvania. With the help of a five-year CASSP grant, Pennsylvania has put into place a children's services bureau in the Office of Mental Health, State Department of Public Welfare; a statewide CASSP Advisory Committee and Minority Initiatives Sub-Committee; a children's mental health specialist in each of the state's four regions; and a CASSP coordinator in each county. The coordinators oversee county-level committees that include representatives from the five state child-serving agencies, service providers, parents, and advocates.

This CASSP infrastructure has enabled the development of systems of care at the local level. Pennsylvania has increased its array of available services from six basic services to 15 services tailored to the individual child or adolescent (although not all services are yet available in all 67 counties). Services can now be reimbursed through Medicaid, the unit of service is the child and family, and all activities related to helping the family—including meeting with other agencies—are billable even if the family is not present. State mental health and education monies and Medicaid (administrative costs) have been used to fund an extensive in-home, competency-based, Family-Based Mental Health Services training program for agency staff. The training program uses videotapes for supervision and results in a certificate in Systemic Home-Based Therapy.

Contact: Anita Thiemann, Office of Mental Health, (717) 787-3459.

Virginia. Virginia's Comprehensive Services Act was passed by the legislature in 1992 to reconfigure Virginia's system of care for troubled youth and their families, and to control the escalating cost of foster and residential care. The initiative is a bold attempt to improve the coordination and integration of services across the state, and to shift decisionmaking for how to spend the monies to the local level.

The Act created the following mechanisms to accomplish its goals: (a) interagency teams, including parent representatives, at both state and local levels; (b) a state Trust Fund to provide "venture capital" for localities to create and expand community-based services; (c) the consolidation of eight state categorical funding streams from four agencies into a State Funds Pool which is distributed to the localities on a formula basis; and (d) the provision of training and technical assistance to the counties as they reconfigure their service delivery systems. Evaluation data from five pilot, state-funded community demonstrations is being used to help design the implementation of the systems of care across Virginia, which began in July 1993.

Contact: Rick Pond, Department of Social Services, (804) 692-1211.

Vermont. Vermont's reform initiative is built on a Robert Wood Johnson foundation-funded demonstration called New Directions. Originally targeting children in out-of-state placements, Vermont has blended financing from child welfare, education, and mental health agencies to develop community-based, individualized services for SED children and adolescents. The state Medicaid plan was revised to provide case management services and treatment in private non-Medicaid institutions.

Nine of Vermont's 13 mental health catchment areas have at least one therapeutic case manager who is responsible for coordinating service delivery and the financial plan to support children's treatment. Therapeutic case managers, with small caseloads, are highly skilled clinicians, system negotiators, and financing experts who provide individualized, wraparound services, working in partnership with families.

Contact: Brenda Bean, Department of Mental Health and Mental Retardation, (802) 241-2630.

Common Features

In summary, it may be useful to highlight some of the key characteristics that distinguish these and other systems of care initiatives from the traditional service systems for children with emotional disorders.

- **Expansion of “intermediate” services.** These communities have expanded the availability of community-based services. Since these services are more intensive than traditional outpatient services, they can often be used as alternatives to hospitalization or residential treatment.
- **Use of an individualized service approach.** These communities are committed to developing a package of treatment services determined by the particular needs of the child and family, and have sought to develop this capacity through more flexible funding as well as other mechanisms.
- **Use of multidisciplinary teams and interagency teams that include family representatives.** At the policy and planning levels, interagency committees have been created to work out interagency agreements and review more complex cases. Parent representatives are generally included on these committees. At the community levels, teams involving agency representatives, members of the family, and, where appropriate, the child meet regularly to develop, implement, and review the comprehensive treatment plan for the individual child and family.
- **Use of case management approaches.** These initiatives, as in other similar system reforms in the child welfare and early intervention fields, have made increasing use of the services of case managers whose primary function is to access and coordinate the array of services the child and the family need. The role and function of case managers differ from site to site. Some communities have been able to utilize highly skilled case managers with clinical training and small caseloads.
- **Financing reforms.** A few communities have been able to develop interagency agreements to blend sources of funding and create pools of flexible funds used to provide individualized, wrap-around services that would not otherwise be funded.

Research on the New Paradigm

(Sources: Burns, 1994; Cole and Poe, 1993; Kutash, Ducknowski, and Sondheimer, 1994; Rivera and Kutash, 1994; Stroul, 1993)

The evaluation of the new systems of care paradigm plays two very important roles in child mental health. First, it informs policymakers and administrators which new treatment approaches and intervention models appear to be promising and need to be implemented more widely. Second, it helps to provide self-corrective feedback to those involved and thereby improves the design and implementation.

Over the past two decades, several reports, especially the Institute of Medicine’s 1989 study, strongly recommended that more resources be devoted to research in child mental health. Yet, in the conclusion of a recent report providing a comprehensive review of research, the authors stated, “research in the area of child mental health services is in its infancy; however, the research base is beginning to expand” (Rivera & Kutash, 1994: 174). Recent efforts are aimed at improving research capacity and building in evaluation as a critical component of the new systems of care demonstrations.

Building research capacity. Several efforts are underway to build research capacity by training researchers and funding more research. As noted, the CASSP program has funded two research and training centers. One of these, the Florida Institute, has conducted a number of conferences for researchers and has published seminal research reviews.

Beginning in 1991, the Center for Mental Health Services began to fund a regular program of research demonstration grants. In general, the studies underway involve assessing the effectiveness of one or more innovative service interventions. A special issue of the *Journal of Emotional and Behavioral Disorders* (Kutash, et al., 1994) published the first set of articles on service demonstrations funded under this grants program.

Lessons learned about evaluation methodology. The systems of care initiatives are still fairly recent innovations, and, thus, the evaluation and research efforts related to them are in the early stages of development. Nevertheless, there are some promising results being reported from several sites. These initial results are discussed in some detail in three publications (Stroul, 1993; Cole & Poe, 1993; and Rivera & Kutash, 1994).

Before highlighting a few of these preliminary results, it is important to take note of some of the complex methodological issues that these evaluations face. Increasingly, scholars conclude that the dominant models of program evaluation—a randomized controlled study of a standardized intervention or a clinical trial—are simply not appropriate or useful as a method of evaluation. In evaluating these highly complex, multi-level, constantly evolving systems interventions in the child and family service field, the goal is to provide an individualized, not a standardized, treatment (see Cohen & Ooms, 1993; and Hollister, forthcoming). Useful studies need to be done using more complex, multi-method models, focusing on the overlapping contexts in which programs are developed and implemented. These evaluations need to identify and assess a much broader array of outcomes at the child, family, program, systems, and community level that are logically related to the intervention. Importantly, they need to identify interim indicators or benchmarks that can be used to assess the progress of the initiative as it evolves, since many outcomes may take years to occur. For example, the cross-site evaluation of the R.W. Johnson MHSPY demonstration faced the challenge of developing an evaluation design for multiple sites. Although each site shared a common goal—to improve the effectiveness and efficiency of services for SED children—and a loose conceptual framework, the initiative was operationalized differently across the sites. The chosen design placed a strong emphasis on qualitative measures (process evaluation). Three types of measures were developed: organizational/financial; case data from a new MIS automated system, and case progress information from a clinical conference team (Saxe, Gardner, & Cross, 1993).

Rivera and Kutash (1994) note that only a handful of studies exist that incorporate a broad systems approach to evaluation, and only four of these efforts employ a control group: the California AB 377 replication research on the Ventura model, Tennessee's AIMS project, the West Virginia Mountain State Network Project, and the Fort Bragg Child and Adolescent Mental Health Demonstration Project. The standard evaluation paradigm typically requires using an independent, outside evaluator who provides a final report.

Many researchers now believe that in evaluations of these complex, reform programs, it is far more useful to involve the clients, program staff, and administrators in the design of the program evaluations. It is also important to use the knowledge gained continuously to improve the program as it evolves (see Cohen & Ooms, 1993).

Preliminary results of selected systems of care initiatives. The reviews of the initial findings of several systems of care initiatives report some very promising results. These are generally agreed to provide strong support for the overall design and direction of the systems of care paradigm. However, the authors caution that these results must be considered preliminary. The methods used, and outcomes assessed, vary from site to site. Combined, these initiatives appear to show that implementing systems of care can result in:

- children being less likely to be placed out-of-home and out-of-state;
- children being less likely to receive services in restrictive environments, but, when they are, their stays are shorter;
- children doing better at home, at school, and in the community on various measures of functioning;
- parents being more satisfied with the services they receive; and
- less reliance on expensive treatment environments, which reduces the costs of mental health services and may also reduce costs of services provided by other child serving systems (child welfare, juvenile justice, etc.).

Implementation outcomes. The final report on the MHSPY demonstration will not be available until early in 1995. The interim report of this cross-site evaluation provided interesting information about the many barriers the sites encountered in implementing these ambitious changes in the organization and delivery of service systems. It also turned out to be much more difficult to implement the automated MIS case management system than initially expected (Saxe, Gardner, & Cross, 1993).

The case conference data noted the many creative contributions to treatment from special educators, social workers, and mental health paraprofessionals. Among the most innovative aspects of the treatment were the collaborations achieved between parents, foster parents, and the professional systems.

The Interim Report reached two broad conclusions.

1. Service systems can develop the capacity to provide comprehensive and coordinated care.
2. State and local contextual factors shape the way the original model of system change is implemented in practice.

Two key principles appeared to drive all of the MHSPY projects: regardless of how they try to accomplish their goals, services should be designed around the needs of the child and services should be based on the family and the community. The authors note that these principles can be viewed as:

an antidote to finance-driven health and social services. For several decades, health and social services have increasingly been influenced by financing concerns and, to some extent, the needs of large, self-regulating service agencies. The needs of the clients, in our case children with emotional disorders and their families, were lost. As money distorted clinical decision-making (e.g., encouraging unnecessary psychiatric hospitalization of children), and the maintenance of organizations became more important than the services they provide, the gap between children's needs and services grew wider (Saxe, Gardner, & Cross, 1993: Executive Summary, pp. 10-11).

IV. Implications and Challenges for Policy

Over the past decade, children's mental health has made great gains. The key components and principles of the new paradigm are well accepted and provide a clear vision for the direction of the field. In a significant number of communities, the vision is being put into operation with some encouragingly positive results.

However, there is still a long way to go. States are struggling to work with other agencies to build the infrastructure needed to support the new systems of care and the approaches to frontline practice. Resources continue to be in short supply. Debates continue on how to target scarce mental health dollars, yet there are also increasing pressures to expand the program scope and to provide more preventive services to populations of children at risk. While the movement to establish and improve the quality and effectiveness of child and family mental health services is gaining momentum, the turbulent health care reform debates are focusing primarily on issues of cost containment, particularly through managing care.

For advocates of the new paradigm, a number of major challenges lie ahead. Policymakers need to understand the impact of the evolving systems of care in terms of both human and financial costs and benefits. Thus one of the most important tasks for the future is to continue to document the results of the system reform initiatives through applying new approaches to evaluation (as discussed above).

In addition to the primary challenge of documenting effectiveness, the following major questions need to be addressed by state and federal policymakers:

- In an era of managed care, how should these systems of care be financed and what should the relationship be between the public and private sectors?
- Who is available to provide these new models of services? Are they trained to work within the new paradigm? What is the federal role in human resource development?
- What can policymakers do to facilitate and promote effective interagency coordination and collaboration needed to make the systems of care model work for children and families?

Although this report cannot explore the answers to these questions in any depth, we will briefly elaborate on them.

Financing Child Mental Health Services in an Era of Managed Care

(Sources: Goldman & Buck, 1994)

Systems of care developments in the public sector are being overshadowed, even swamped, by the advance of managed care in the private sector. The debates about the direction of national and state health care reform raise difficult and troubling issues about how to incorporate the new paradigm into the private sector and how the public and private sectors will intersect with each other.

Mental health advocates entered the health care reform debates of 1993-1994 with some anxiety. A coalition of national organizations concerned with mental health, the Mental Health Liaison Group, and many other professionals and individuals, worked vigorously to develop a consensus on how health care reform should address mental health needs. They were concerned that uninformed fears

that insuring the “worried well” would bankrupt the system might result in less, not more, adequate coverage. The coalition strongly urged that mental health benefits should have parity with physical health and that a wider range of services should be covered. Child and family advocates were encouraged by the bold recommendations for ways to incorporate the systems of care principles and model into the new health care alliances put forward by the White House working group on mental health and substance abuse of the President’s Task Force on Health Care Reform. These were considerably scaled back in the Health Care Security Act introduced in Congress by the Administration. However, this bill did expand present coverage for mental health services to the currently uninsured and for those with minimal or no benefits. It also covered a wider range of benefits, including a variety of nonresidential alternatives, and put forth the goal of parity for the year 2001. In addition, all the other legislative health care reform proposals signified a considerable improvement over the current situation in terms of mental health coverage.

In the end, while initial high hopes for the enactment of substantial reform were disappointed, there is broad agreement that the mental health community, and child mental health in particular, improved its position in the debate. The debate itself, and the strong advocacy of Tipper Gore and others, succeeded in providing much-needed public education about mental health in general, and the needs of children and families in particular, which should be helpful in future reform discussion.

As this *Background Briefing Report* is published (nearly one year after the seminar in November 1994), the Republican Congress concentrates on reducing Medicare expenditures and scaling back the Medicaid entitlement. Critics worry that if states are left to determine eligibility requirements for Medicaid, for example, children with mental and emotional illnesses may not be properly served. Whatever happens at the federal level, many states and communities are moving ahead with reform. An increasing number of states are providing Medicaid-funded services under a capitation basis. And in the private sector, managed care (in a variety of shapes and forms) is becoming a reality for increasing numbers of Americans.

There is not much information available about what kinds of models are evolving in the private sector for delivering child and family mental health services. We do know that some managed care companies have experienced many of the same skyrocketing costs of funding institutional care as the state agencies. A number of innovations are underway in the private sector, largely driven by progressive corporations, such as Honeywell and Aetna and the more innovative, behavioral managed care companies. They are attempting to design an “unlimited” but managed mental health benefit that includes some of the same features as the “systems of care” in the public sector—that is, coverage for a broad range of services, including some of the new technologies of in-home services, no pre-ordained day or visit limits, and, in some cases, families are included as partners.

A study currently being conducted by the Human Service Collaborative, funded by the Center for Mental Health Services, seeks to identify and describe what kinds of private sector systems of care are being put into place. The report will be available in early 1995.

There is both optimism and concern for the future. Some believe that the paradigm shifts entailed in the systems of care model are compatible with the goals and principles of managed care. They point to examples of several of the systems of care demonstration initiatives. They see managed care as providing both an incentive and an opportunity for forging more effective collaborative models of practice between mental health and physical health providers. On the other hand, many are concerned

that the managed care companies have neither the incentives nor the knowledge necessary to create the intermediate services that are so badly needed. Moreover they have no experience in coordinating services with other systems. Many fear that the needs of the severely and chronically ill will be ignored in the new environment of managed competition.

Human Resource Development and Staffing Needs

(Sources: Combrinck-Graham, 1990; Duchknoski & Friedman, 1990; Pires, 1992)

The success of the new system of care paradigm rests heavily on the capacity of staff to administer and deliver the services in new, collaborative ways. Therefore, the issues of staffing and human resource development in child mental health need greater attention than they have received to date. In a survey designed to assess workforce issues in the southern states region, 69% of the respondents said they considered workforce issues to be at least as important as, or more important than, securing adequate funding (Pires, 1992). There are a number of reasons for their concern:

1. Mental health professionals, especially child psychiatrists, are in short supply. Those that exist now practice primarily in the private sector. (In the 1960s, more skilled mental health professionals worked in community mental health centers than they do today.)
2. The issue of retraining those who are currently providing services is paramount. Neither the training nor the experience of the existing cohort of mental health professionals has prepared them for working in the variety of community-based, intermediate care settings that are becoming part of the new systems of care. Most clinicians were trained in the medical mental health paradigm and are already struggling with the demands of managed care companies to provide short-term treatment. They have little experience or training in how to do systems-based assessments and case management, work in culturally competent ways with diverse populations, or work in partnership with families.
3. The curriculum currently being offered in the university-based training programs to prepare new mental health professionals to work with priority populations in the systems of care models and in the public sector needs to be reexamined and changed. Over the years, the university training programs have been largely isolated from the systems of care movement. Although a few attempts are underway to incorporate the new knowledge and approaches, there is still much to be accomplished.
4. The roles of skilled mental health personnel need to be reexamined. Their special skills and knowledge need to be used parsimoniously. Even if it were desirable, it is unrealistic to believe that only mental health professionals should be responsible for providing all the mental health treatment that children and families need. Moreover, the new paradigm emphasizes the necessity of mobilizing other resources in the child's life, including family members, teachers, and others considered to be part of the treatment team. Mental health professionals need to learn to assume new roles as consultants, trainers, planners/managers, and coordinators in the development and implementation of individualized treatment plans. They also need to learn to communicate and collaborate with the staff of other child serving systems.

The federal government has a special responsibility to address these workforce issues. In earlier decades, the federal mental health agency, NIMH, funded the bulk of the training fellowships for

mental health, but these training dollars have been severely cut back. The major challenge that lies ahead is for federal policymakers to develop strategies to accomplish these shifts in human resource development in child mental health with minimal new dollars.

One option would be for the Center for Mental Health Services to collaborate with many of the other child- and family-serving federal agencies—for example, the Children’s Bureau—who are facing similar issues to pool existing training resources. Many activities could be jointly funded such as developing some of the core competencies to incorporate in current academic and inservice curricula and sponsoring cross-system training conferences. Another option being suggested is to define child psychiatrists—and perhaps allied mental health professionals providing services to children—as primary health care providers so that they can benefit from the new monies expected to be forthcoming from the Health Care Financing Administration for expanding the number primary care providers.

Coordination with Other Child and Family Serving Systems

As is often noted, a key to putting the principles of the new systems of care paradigm into practice is close coordination and collaboration between child mental health and other child serving systems—principally child welfare, special education, juvenile justice, and early intervention. (Of course, it would also be beneficial for child mental health agencies to work closely with agencies that provide mental health, substance abuse, and correctional services to parents.) This collaboration needs to occur at every level—clinical, administrative, and policymaking. In many states and communities, some important first steps have been taken. Service providers and state officials are sitting down around a table to plan, allocate resources, and make decisions together for the first time. Nevertheless, many barriers stand in the way and impede progress. It is painstakingly difficult to break down the regulatory and administrative walls between different programs. The long tradition of shifting responsibility for troubled children from one program to another is hard to overcome. Too often, SED children are seen by the other systems as either hopeless or “bad.” However, some promising initial steps toward improving collaboration between child mental health services and both special education and child welfare are underway (APWA & NASMHPD, 1994; Chesapeake Institute, 1994).

The new paradigm in child mental health is not occurring in isolation. Similar system reform initiatives, funded by both public and foundation monies, are underway in many other program areas. For example, new federal legislation, the Family Preservation and Support Services Program (FP/FS), provides grants to states over the next five years to develop coordinated, comprehensive systems of care for children served by the child welfare system, or at risk of being so. State child welfare agencies are currently involved in a broad-based, very inclusive planning process that involves a broad range of stakeholders including parents. Many of them are turning to their colleagues in child mental health to build on their experience over the past few years in the CASSP and other initiatives.

It is easy to proclaim adherence to the mantra of coordination and collaboration. The urgent task is to develop a more detailed understanding of the concrete barriers that make it difficult to coordinate and collaborate between different systems, and to identify specific ways of surmounting them.

Organizational Resources

While there are a number of national organizations that address issues related to children's mental health, such as the National Mental Health Association, the American Psychological Association, the Judge Bazelon Center for Mental Health Law, and Zero to Three, we have chosen to list below only those organizations that have as their sole focus the mental health needs of children and adolescents.

American Academy of Child and Adolescent Psychiatry (AACAP)

Founded in 1953, the Academy represents over 5,000 child and adolescent psychiatrists. AACAP members actively research, diagnose, and treat psychiatric disorders affecting children and adolescents and their families, and the Academy supports this work through a variety of programs, including government liaison, national public information, and continuing medical education.

Contact: American Academy of Child and Adolescent Psychiatry, 3615 Wisconsin Avenue, NW, Washington, DC 20016, (202) 966-7300, (202) 966-2891 fax.

Center for Mental Health Services, Child, Adolescent, and Family Branch

(Substance Abuse and Mental Health Services Administration, Public Health Service, U.S. Department of Health and Human Services)

The Center for Mental Health Services provides leadership at the federal level to treat mental illness, promote mental health, and prevent the development or worsening of mental illness. Its activities facilitate the application of scientifically established findings and practice-based knowledge to prevent and treat mental disorders and to improve access, reduce barriers and promote high quality, effective programs and services for people with - or at risk for - these disorders. The Child, Adolescent, and Family Branch in the Center's Division of Demonstration Programs administers a number of programs, including Child and Adolescent Service System Program (CASSP) and the Comprehensive Community Mental Health Services for Children Program (the Child Mental Health Services Initiative).

Contact: Center for Mental Health Services, Child, Adolescent, and Family Branch, 5600 Fishers Lane, Room 11C-17, Rockville, MD 20857, (301) 443-1333.

Federation of Families for Children's Mental Health

The Federation of Families is a national parent-run organization that focuses on the needs of children and youth with emotional, behavioral, or mental disorders and their families. The Federation provides an opportunity for family members to work with professionals, policymakers, and other interested citizens to improve services for their children, and to set a national agenda for children's mental health. The Federation has state and local chapters and affiliates.

Contact: Barbara Huff, Federation of Families for Children's Mental Health, 1021 Prince Street, Alexandria, VA 22314-2971, (703) 684-7710.

Human Service Collaborative

Human Service Collaborative is a policy center dedicated to improving services for children and families. It provides assistance to agencies and communities to achieve effective human services for children, young adults, and families that are individualized, comprehensive, family-centered, community-based, and culturally sensitive; collaboration and service integration across agencies and jurisdictions; and cohesive, flexible systems of care for children, youth, and families at risk.

Contact: Sheila Pires, Human Service Collaborative, 2262 Hall Place, NW, Suite 204, Washington, DC 20007, (202) 333-1892, (202) 333-8217 fax.

Mental Health Services Program for Youth, National Program Office, Washington Business Group on Health

The National Program Office of the Robert Wood Johnson Foundation's Mental Health Services Program for Youth (MHSPY) is a program of the Washington Business Group on Health in Washington, DC. The national office provides technical assistance and direction to the eight grantees, typically in the form of mentoring the sites as they work to bring about system reform on multiple levels. The Washington Business Group also has received a federal grant to provide technical assistance to the Child Mental Health Services Initiative sites.

Contact: Ellen Kagen, Mental Health Services Program for Youth, National Program Office, Washington Business Group on Health, 777 North Capitol Street, Suite 800, Washington, DC 20002, (202) 408-9320.

National Alliance for the Mentally Ill—Child and Adolescent Network (NAMI-CAN)

The National Alliance for the Mentally Ill (NAMI) is a grassroots, self-help, support and advocacy organization for families and friends of people of all ages with neurobiological disorders. NAMI-CAN (a council of NAMI) is composed of families and friends of children and adolescents with serious neurobiological disorders which are included in the "seriously emotionally disturbed" school definition. NAMI-CAN advocates specifically for those with bipolar disorder, severe depression, schizophrenia, schizo-affective disorder, obsessive compulsive disorder, anxiety and panic disorder, attention deficit hyperactivity disorder, autism and Tourette's syndrome, among others.

Contact: NAMI-CAN, 2101 Wilson Blvd., Suite 302, Arlington, VA 22201, (703) 524-7600, (703) 524-9094 fax.

National Technical Assistance Center for Children's Mental Health

(formerly the CASSP Technical Assistance Center)

Since 1984, the Technical Assistance Center has been serving as a national policy and technical assistance resource center to improve service delivery to children and adolescents with, or at risk of, serious emotional disturbance and their families. The Center assists states and communities in building systems of care, with an emphasis on system planning, interagency coordination and collaboration across child-serving systems, financing, service development and integration, human

resource development, family involvement, cultural competence, early intervention, and service issues for special populations of high-risk children and youth. It receives funding from the Maternal and Child Health Bureau, the Center for Mental Health Services' Child, Adolescent, and Family Branch, and the Administration on Children, Youth, and Families.

Contact: Sybil Goldman, the National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center, 3307 M Street, NW, Washington, DC 20007-3935, (202) 687-5000.

Research and Training Center on Family Support and Children Mental Health, Portland State University

The Center focuses on improving services to families whose children have mental, emotional, or behavioral disorders through a set of related research and training programs. Research efforts are clustered around family participation in services, family participation at the policy level, families and out-of-home care, and evaluation of family organizing efforts. It has published numerous reports on these issues, and also regularly produces a newsletter, *Focal Point*. The Center is funded by the National Institute on Disability and Rehabilitation Research and the Center for Mental Health Services.

Contact: Barbara Friesen, Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, OR 97207-0751, (503) 725-4040.

Research and Training Center for Children's Mental Health, Florida Mental Health Institute

Created in 1984, the Research and Training Center conducts research, synthesizes and disseminates existing knowledge, provides training and consultation, and serves as a resource for policymakers, researchers, parents, and advocates to develop an effective service delivery system and address the need for improved services for children with serious emotional disturbances and their families. The Center is funded by the National Institute on Disability and Rehabilitation Research and the Center for Mental Health Services.

Contact: Robert Friedman, Research and Training Center for Children's Mental Health, Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612-3899, (813) 974-4661, (813) 974-4406 fax.

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Highlights of the Seminar

Held on November 18, 1994, in 210 Cannon House Office Building.

Moderator **Theodora Ooms**, director of the Family Impact Seminar (FIS), welcomed participants and introduced **Dr. Bernard Arons**, director of the Center for Mental Health Services (CMHS), the office which funded this seminar.

Arons welcomed the panelists and participants and said that this seminar was important because “comprehensive, integrated, family-centered, community-based systems of care are critical to meeting the mental health needs of the child and his/her family, both today and in years to come.” He noted that children who receive mental health services in coordinated systems of care are less likely to be removed from their homes; they do better in school; they stay in school; and they have fewer run-ins with the law. Arons added that systems of care reduce mental health costs by emphasizing early diagnosis and treatment and by avoiding more costly hospitalization. In the longer term, they reduce the burden on the child welfare, education, and juvenile justice systems.

Ooms introduced **Jane Knitzer**, the seminar’s first panelist, by saying that it was Knitzer’s report for the Children’s Defense Fund, *Unclaimed Children*, which really “ignited” some action in the child mental health community over a decade ago. Knitzer is currently the deputy director of the National Center for Children in Poverty at the Columbia School of Public Health.

Knitzer provided some background on children’s mental health. According to epidemiological estimates, 14 to 20 percent of all children have emotional and behavioral difficulties warranting some kind of formal intervention. Estimates also suggest that at least 3 to 5 percent have serious emotional and behavioral disorders, with some indications that the prevalence is increasing. Emotional and behavioral disabilities cut across class and race, affecting all kinds of families, although there is some evidence to suggest that children from low-income families are disproportionately identified. While the roots of emotional and behavioral disorders are complex and not fully understood, the general consensus is that there is some interaction of biological, environmental, and other factors. There also is no “neat” way to characterize children with these disorders. The patterns vary enormously, as do the elaborate psychiatric diagnostic categories which accompany them. While one child cries incessantly, another is impulsive, and yet another is disruptive in the classroom. She added that children and adolescents with emotional and behavioral disorders are found in all public systems, not just mental health, and sometimes not even in mental health. Traditionally, mental health departments as well as other systems have paid little attention to children with mental health needs, yet meeting these needs is clearly an interagency challenge.

Knitzer then described the changing view of children’s mental health. In 1982, public policy was almost nonexistent in this area. Service options were limited to outpatient therapy or inpatient therapy; sometimes residential treatment; even less frequently, options for day treatment. And when children were served, they were served in isolation. The new paradigm, according to Knitzer has brought with it many changes. She discussed the following working principles:

- Families should be partners and collaborators in the effort to improve family support, educational, and mental health services. Families are seen less often as the cause or part of the

problem, but rather as resources and partners in planning and implementing services, building on their strengths. Professionals have to be resocialized around this principle.

- Services should be flexible and individualized, and maximize opportunities for children to remain in normal kinds of settings. She noted that children with emotional problems often are social outcasts. They must learn to engage in and be part of social processes, and practice these skills. In the new framework, mental health dollars can be used for this purpose. Services also should be in place to respond to crises.
- Intensive services should be provided in natural settings, such as schools, homes, early child care settings, child welfare offices, and juvenile justice. Mental health professionals must work collaboratively not only with families, but with other systems.
- Cost-effectiveness, outcome data, and cost containment count in a changing fiscal human service environment.
- There must be a community-level infrastructure behind a system of care, and the state and federal policy to support it.

She also acknowledged recent and exciting advocacy developments, such as the development of the Federation of Families for Children's Mental Health.

According to Knitzer, much progress has been made in terms of policy developments in the last decade. CASSP, a \$1.5 million federal grant program to states, was initiated in 1984. It was a catalyst for mobilization. The Robert Wood Johnson Foundation then funded seven projects through which states and communities partnered to implement systems of care. It set the stage for the new federal Children's Mental Health Service Initiative, which is now spreading the systems of care to other parts of the country (see p. 22).

Building on these initiatives, Knitzer outlined the following challenges for the future:

- *Ensuring access to organized systems of care.* When *Unclaimed Children* was published, two-thirds of the children who needed mental health services received no services or inappropriate services. Even today, only a very small group of children is being served intensively and well.
- *Focusing on the mental health needs of younger children and families.* Adolescents and older children have received the most attention and services, while the zero-to-six population has not been addressed in a systemic way. Mental health groups still need to link with the early childhood community. She recommended reexamination of the Child Care and Development Block Grant, Head Start, and Part H of the Individuals with Disabilities Education Act with this in mind. And at-risk older children, as well as children with identified problems, should be served.
- *Sustaining the capacity to continue family focused, collaborative services in a changing health care financing environment.* "How do we protect the cross-system, collaborative work in a managed health care environment?" she asked.
- *Training the next generation of professionals.* Much effort has been spent retraining people out in the field, but more energy should be focused on the next generation of professionals so they don't have to be resocialized. The federal government can be helpful in this area, and has a tradition of doing so.

Ooms recognized director Gary DeCarolis and Judith Katz-Leavy, who heads the Children's Mental Health Services Initiative, both of the Child, Adolescent, and Family Branch of CMHS.

The second panelist, **Stephany Van Dyke**, is the mother of Chelsea, a 14-year-old girl with serious emotional and behavioral problems, whose story poignantly illustrates the difficulties families face in getting the services they and their children need. Ms. Van Dyke is a pediatric nurse practitioner. She recently got a job in Arizona, and is attempting to establish residency and access services for Chelsea so that the whole family can move there from Vermont. Van Dyke's husband continues to reside in Vermont so that Chelsea can maintain her placement in a group home until they can all move to Arizona. The Van Dykes have other children, ages 22, 18, and 12. The Van Dyke family adopted Chelsea when she was two years old; they did not know nor expect that she had an emotional disability, which began to emerge at age four.

Van Dyke described Chelsea as "a precious, wonderful person who is very challenged," and then provided a vivid portrait of her disturbed behavior. As a preschooler, Chelsea had unpredictable rages that lasted up to two hours almost every day. In elementary school, she was aggressive toward other children. In those early years, she could only stay in a group of other children for five minutes, and spent most of her time being separated from others. Chelsea had difficulty loving or trusting others. She was in first grade when she smiled at school for the first time. She was eight years old before she was able to hug her parents. Today, Chelsea urinates in containers and saves them, or urinates on piles of clothing and carpeting in her room. She has severe anxiety attacks that prevent her from entering unoccupied rooms, sometimes even going into a shower. She destroys property and she steals. She has very compulsive, odd eating habits. She will drink a jar of spaghetti sauce, eat a cube of butter "...all very secretively, all in some odd little place."

Van Dyke discussed how her family life was affected by Chelsea's behavior. Every bedroom in the house had to be key-locked so that Chelsea would not steal. Any special food, like chocolate chips for cookies, had to be locked in a bedroom. Van Dyke's oldest daughter became critically ill a year ago, but couldn't come home from college because living with Chelsea would have added to her medical problems. Chelsea could never be left alone unsupervised, and still cannot be today. Van Dyke could not work full-time since Chelsea came into her family. Van Dyke has spent much of her time taking care of behavior problems at school, taking Chelsea to therapy, and attending meetings. Because Chelsea's behavior was so unpredictable, they never invited people over to their house nor could they make long-term commitments. They didn't know what life would be like in a week. Their world was very narrow and their resources were rapidly dwindling. The day-to-day stress and demands left the family drained, physically and emotionally.

Chelsea has been seeing a psychiatrist since age four. Over the years, Chelsea accumulated the diagnoses of chronic depression, attention deficit disorder, post-traumatic stress syndrome, and oppositional defiant behavior disorder. Van Dyke pointed out that these diagnoses did not open doors to services or support, nor did they even begin to describe Chelsea.

The family has never been able to access services on their own, nor have they been provided with services simply because they needed them. Their pediatrician made it possible for the family to get respite care when Chelsea was eight. However, it took three years for the psychiatrist to get the school to provide special education services. A year ago, when the Van Dykes reached their limit and felt they could no longer care for Chelsea on their own, they asked for help, but were told Chelsea's

problems weren't severe enough. They were told that Chelsea could only receive services if someone actually abused Chelsea so that she would be removed from their home. Of course, the Van Dykes' children also would be at risk for removal. The Van Dykes continued to care for Chelsea on their own.

The school system made a referral only when Chelsea's problems there became more unmanageable. Chelsea was assigned a tutor-mentor to be with her at school, and wraparound services were then put into place. When Van Dyke realized that most of Chelsea's time at school was spent sitting in the hall with an adult, she then negotiated a new plan with the school. This plan included art therapy; regular time with her therapist; collating and filing at the school district office; socializing animals at the Humane Society; and cleaning stalls at a horse farm. Chelsea felt good about herself and her grades went back up.

After about two weeks with the tutor-mentor, professionals finally recognized that Chelsea's behavior was not going to be managed at home under this plan, and a referral was made to a therapeutic group home. State lawmakers had to put pressure on the insurance company to provide the necessary mental health care coverage for the family. Within two weeks after placement, professionals recommended that Chelsea learn basic skills with one person in an apartment. Tutor-mentors would live with her, one-on-one, around the clock.

When Chelsea was getting ready to transition to an apartment in March, Chelsea's father found out his position would be eliminated at the end of the year. Mrs. Van Dyke was offered a full-time job in Arizona, so they began at that time to try to put services in place for Chelsea there. Professionals in Arizona have refused to talk to the Van Dykes, even with professionals in Vermont calling to help. The Van Dykes were told they had to establish residency in Arizona first. As a result, Van Dyke moved to Arizona in August, while her husband remains in Vermont, so that Chelsea's care is not disrupted. Van Dyke continues to attempt (unsuccessfully) to talk with Arizona mental health professionals, and the school refuses to address the situation until mental health does.

Van Dyke reminded participants that families with children with emotional disabilities often cannot speak up because all of their time and energy is consumed with day-to-day living. They face immense obstacles, in addition to pressures faced by all families, such as a lack of job security which requires families to move. She feels fortunate that she currently has services through which Chelsea is cared for by others. These services allow her to spend the time and energy necessary to seek services and speak publicly about this. "I continue to advocate for better services," she said. "My daughter can grow to be a very bright, capable, contributing member of this society. Yes, she will need supports for the rest of her life. But she can pay back society in many, many ways if we support her now."

Ooms underscored the fact that there are many families out there like Stephany's — many who do not have the same resources or level of support. Service systems also vary a great deal from state to state and community to community. And she reiterated that we have a lot to learn from families.

The third panelist, **Dr. Regenia Hicks**, is deputy director of Child & Adolescent Services in Mental Health/Mental Retardation for Harris County in Texas, but had previously worked for the state of Maryland. Dr. Hicks discussed the state's role in achieving improved services, the new paradigm and coordination with other systems, as well as her special interest in cultural competence.

Dr. Hicks began by telling a story about a people who are now extinct. These people were cliff dwellers, living on the top of a very high mountain. Unfortunately, the cliff dwellers were losing their

children; that is, the children were ambling around, and many of them were falling off the side of the mountain. The elders got together and after many rounds of debate around the “intercollaborative table,” they came to the conclusion that they would build a hospital at the base of the mountain so that when the children fell off the mountain, they could receive services at the bottom.

Hicks compared children’s mental health services to the hospital at the bottom of the mountain — the weak link among the child serving systems. The system has been very underfunded and ignored. There is no poster child for children’s mental health, and oftentimes there is not a strong advocacy voice. Because of the supports and services that are not available for families of children with mental health problems, they have not been able to advocate in the way that families with children with other serious disabilities have.

Hicks noted that all state systems are subject to mandates that address specific categories of children. These mandates allow state systems to treat, to contain, and to protect. Often these mandates do not in any way fit together to provide a base of care or support for families. In most states, for example, a family can only access some level of residential care if their child is in the child protective services system, a system for abused and neglected children.

Hicks stressed the importance of having vehicles at the state level which pull together all of the child-serving agencies. Maryland has the Governor’s Subcabinet for Children, Youth and Families, which is chaired by the special secretary of Child and Family Services. All of the major agency heads are part of that Subcabinet, as many of the agencies are serving the same families. As an example, Chelsea has needs from the mental health and the education systems, but is also at risk for involvement in the juvenile justice system because of her stealing. Many kids that steal have serious emotional problems. Hicks added that children of color are much more likely to end up in the juvenile justice system. An interagency vehicle, then, is critical.

In Maryland, all of the child-serving agencies came to agreement about whom to target with state dollars for children’s mental health and what services will be provided. In Maryland communities, child serving agencies collaborated and pooled resources and families were involved in the planning.

In Texas in 1987, Hicks was the first director of children’s mental health. Texas had state hospitals and limited outpatient services. With the first line-item appropriation in 1988 of \$2 million, five model systems development programs were funded.

Hicks cited some barriers and difficulties faced by states when trying to implement the new collaborative paradigm:

- Moving away from institutional services. In many states and communities, institutions are the major employers, so reducing institutional placements and creatively reallocating dollars might be met with resistance. As a possible solution, staff who would be displaced can be reassigned to community-based services.
- The state has to give up control. Turfism, or “this is my money and my kid” can get in the way of agencies’ collaborating. At the same time, the state must empower communities to determine what needs they have and to design services that meet those needs.

As all communities are different, the “complexions” of these communities are different as well. It is estimated that by the year 2000, at least 30 percent of the children in this country will be children of

color. The preponderance of children served by state service delivery systems are children of color, including children with different cultural, ethnic, and linguistic backgrounds. These backgrounds include belief and value systems that influence how health care is viewed and how and whether services are sought. As Americans are not one homogeneous group, to effectively serve kids and families, services must be *culturally competent*.

Cultural competence implies that service planners and service providers examine the state's ethnic and racial demographic profile, both current and projected. In many communities, there will be a need to have more bilingual and bicultural professionals, who are in short supply. Hicks pointed to the need to reexamine such issues as training, salary scales, hiring practices, and retention. Incentives for learning second languages might also be provided.

In summary, state providers of services don't often talk about prevention because there are so many children who are so seriously involved that they must "keep building those hospital beds at the bottom of the mountain." But Hicks believes that it is also possible "to build some fences. I think the direction that we're talking about is in building bridges *and* building fences. Those bridges need to cross the agencies. The fences really need to surround the children and families."

Randall Feltman, the final panelist, is director of Ventura County (CA) Mental Health Services, where for several years they have been working to build a system of care. Feltman stated that those who work in local government often feel "squeezed" between the urgent needs of children with emotional and behavioral problems and their families, and the laws, policies, regulations, funding formulas, and categories that people at the federal or state level impose on those on the front lines. With limited resources, service providers must offer very intensive and effective services to make a difference in the lives of children who have serious problems. It is not possible to serve everybody, so difficult choices must be made.

Traditional mental health services, as Feltman saw them, consisted of mental health staff talking to each other, working in clinics, doing psychotherapy in 50-minute hours, and hospitalizing people. People who came in were served on a first-come, first-served basis. These clinics were very staff-friendly, not customer-friendly, environments. A system of care is completely different, according to Feltman. He credits the federal government with moving the field toward a system-of-care philosophy.

Feltman described a system of care as "a specific method of organizing public and private human service resources within a community to achieve the highest benefit at the lowest cost." He then outlined the characteristics or "standards" of a system of care:

- *Define at the local level a specific client population that can be identified and whose needs can be understood.* It is not enough to serve whoever comes in with a DSM-IV diagnosis on a first-come, first-served basis. With limited resources, some must take priority over others. If more resources become available, then other target populations can be served.
- *Clearly define goals and outcomes that drive the system of care.* In Ventura County, the goals are clear: help children with serious emotional problems stay with their families, stay in the community, stay out of trouble with the law, and stay in school and learn. A system of care has to have observable, measurable outcomes that drive the system because it is accountable to taxpayers.
- *Establish public and private partnerships within the community.* Mental health should not work in isolation, because it alone cannot serve a multi-problem child and family. Kids with

serious emotional problems have school problems. There may be child abuse or there may be delinquency problems, special education problems, drug and alcohol problems, and medical problems. Mental health has got to work in partnership to be effective and has to leverage the expertise and funds of other resources.

- *Develop services that are community-based and comprehensive so that they involve child-centered and family focused services.* Services should be provided in natural environments. In Ventura, very few services, perhaps 25%, are in clinics. Most are in schools, foster homes, detention centers, and in the homes of children themselves. Services and professionals also need to increase their competence by understanding more about different cultures. He pointed out that everyone, no matter what his/her culture, is culturally incompetent and, therefore, must seek increased understanding of cultures other than their own to increase their cultural competency.
- *Have continuous internal evaluation of outcomes.* Agencies and other providers must include internal and continuous measures of performance of the system of care.

Because resources have been so limited in California, Ventura County has been forced to limit services to children who are at highest risk. The public sector has more legal responsibility for a child whom the government has taken away from a parent because of child abuse, for example, than it does for other children. In terms of liability, they must look at who will cost the most, and target those children who are at risk of out-of-home placement through the child welfare, juvenile justice, special education, or mental health systems. Most importantly, if costs are reduced, funds can be shifted or reallocated to further develop a local system of care.

Feltman said they measure outcomes such as the number of children placed outside their homes with public money; delinquency recidivism for kids identified with a mental illness diagnosis; and for seriously emotionally disturbed special education pupils, school attendance and academic progress. Because Ventura County has been successful in showing the outcomes, including possible cost savings, they have been able to reinvest money back into the community. In California, Feltman points out that there are \$500 million in Title IV-E group home placements alone. Judges have placed 15,000 (out of 32 million) kids in California in group homes. These placements cost between \$30,000 and \$120,000 a year. If mental health, child welfare, probation, and special education were to work together and reduce those placements by 20 percent with aggressive community-based systems, there would be \$100 million (20 percent of \$500 million) to shift back, at no additional cost. Ventura County has thrived by achieving outcomes that lower costs for hospitals, detention centers, state hospitals, and residential programs funded through IV-E that involve local, state, and federal costs.

Ventura County has been able to continue to provide these services in a “downsizing” recession economy by measuring outcomes, developing a management information system, saving money, and then planning ahead and saying, “we want this money in our community, instead of in distant residential placements and hospitals.” The system of care framework is a framework for change that could make a lot of difference in the lives of these children and families around the country, he concluded.

Points Made During Discussion

A participant from CSR, Incorporated, commented that, as Van Dyke made very clear, it requires a high level of energy, commitment, verbal ability, and stamina to pursue services for emotionally

disturbed children. She wondered how single parents, particularly those with mental health or substance abuse problems themselves, can take care of their children's mental health needs as well. Knitzer commented that wraparound and respite care become even more critical for single parents, for whom the stress is enormous. To maintain children in these families, respite care with trained people who can do something constructive with the children should be paid for, and these services should be respectful of what families want. She also cited the enormous "disconnect" between the adult system and the children's system. Therapists will see an adult mentally ill person for years and never know they have a child — a critical issue relevant to younger children. Ooms added that this is also true with parents in the substance abuse system.

Hicks acknowledged that the current system for family involvement is really set up for families with resources, supports, and an understanding and sophistication about how to make things happen. Families are very diverse, so outreach should be examined, particularly in terms of cultural competence. She also suggested more pairing of parents.

Feltman agreed, stating that it is a question of access. From a system standpoint, "we want to have multiple points of entry and a single point of responsibility (once they are in) for a child and a family." Every special education class, foster home, mental health site or practitioner, mobile emergency team, and probation officer then becomes a potential point of entry into the system of care.

Another participant asked what services are available for the siblings. She thought the schools, in particular, might see behaviors from siblings which warrant attention.

Van Dyke stated that her 12-year-old has learned a great deal about working with handicapped people, so her teachers like to pair her with a handicapped child. Van Dyke had to ask the teachers not to, so that her daughter could choose her own friends. She added that getting help or services for the rest of the family is very difficult given limited resources. For another member of a family to see a therapist and have it covered by insurance, that individual would have to have a diagnosis. In order for Van Dyke to see a psychologist without Chelsea's being present (even for sessions about Chelsea), she had to be given the diagnosis of "anxiety disorder." Knitzer agreed that the strain on siblings is often ignored, but the Federation of Families for Children's Mental Health has conducted some workshops, and support groups are beginning to spring up. In Ohio, the Department of Mental Health has been providing support and recreation services for children with either a parent or sibling who is mentally ill or emotionally disturbed, according to Hicks.

A participant from the CDM Group asked how the mental health needs of a 3- or 4-year-old can be addressed, particularly if s/he has not yet been diagnosed.

According to Knitzer, programs for very young children who are "at risk" vary a great deal. With young children, even more effort needs to be put into working with their caregivers and the families. Knitzer currently is working on a national study of young children and mental health and family support issues.

Feltman stated that "the public system deals with children that are troubling [to others], not troubled." But early intervention could be very cost effective if these kids and families can be reached sooner. Most pediatricians are very poor diagnosticians of emotional and behavior problems in young children, but Michael Murphy from Harvard is working on a pediatrician's assessment tool. Head Start is another important means to identify kids early and make use of existing service dollars. In addition, special education has a legal responsibility to identify children very early on who are headed for special education and to work with the families.

Van Dyke commented that everyone knew early on that Chelsea could only function in one-on-one situations, yet all that was available was psychotherapy. If more creative services were available to address this problem early on, Van Dyke believes, Chelsea probably would not have to be in such costly care now.

Emily Fenichel, from ZERO TO THREE/National Center for Clinical Infant Programs, said that her organization is doing a lot of good work with the very young population, including a new schema for how to diagnosis their difficulties and support their families (see BBR, p. 5). She added that much has been learned in the past 15 years about how to support families and children in their social and emotional development, and also how to identify emerging difficulties. She also has a project which examines the emotional foundations for school readiness.

Another participant from ZERO TO THREE asked what is being done to provide support and training to staff to implement more family-centered services.

Feltman said there are a number of states and localities that incorporate mental health into the eligible providers for IV-E child welfare training dollars. He is working with drug and alcohol, mental health, schools, child welfare, probation, and health to open up training to staff across agencies related to serving these families. Interagency training allows staff to get to know each other and ask questions, which is an education in itself, and the federal government helps pay for it. States and localities can utilize this subsidized training now, without any change in law.

A participant from Making the Grade asked if there is a role for school-based health centers, since they were designed to be comprehensive and multidisciplinary. Hicks responded that there definitely is a role for them. Previously, mental health practitioners had families come to them, but the school environment is the natural environment that contains children and families, so there needs to be a mental health presence there. Maryland, in their school-based health initiative, was able to make use of EPSDT (Early and Period Screening, Diagnosis and Treatment)/Medicaid dollars. These centers also provide opportunities for staff from Child Protective Services, juvenile justice, and others to work there for more “one-stop shopping.”

Van Dyke added that this is also true of private professionals. In Vermont, a group of psychologists and therapists in private practice contracted with Chelsea’s school to provide group therapy. The school bused kids after school to the facility where they had their group therapy and then went back to the school and were taken home. She was able to continue working when she otherwise would have had to transport Chelsea to and from school.

Feltman said that people at the state and community level often say that the federal government has tremendous difficulty talking to each other across program and department lines. Child mental health is the big loser because “mental health services must be provided in partnership in order to be effective.”

Huff clarified that at the federal level, the Center for Mental Health Services recently has taken a lead in coordinating with representatives from the Administration on Children, Youth and Families, criminal justice, special education, maternal and child health, and others to discuss cross-cutting issues.

Chart I

Changing Mental Health Assumptions

Old “Disease” Paradigm	New “Systems” Paradigm
<ul style="list-style-type: none"> • Mental illness resides in the individual. • The target of intervention is the individual. • Treatment is provided by a mental health professional. Psychiatrists usually play the central role. • Diagnosis and treatment are based on an assessment and the remediation of pathology and deficits. Treatment goals are to change feelings, thought patterns and/or behaviors of individuals. • When emotional, mental or behavioral disorders are deemed to have biological origins, medication is the primary treatment. Parents may be provided with information, advice, training and/or therapy to change their behavior towards the child. • Parents are important informants about past or current interactions with their children. The parents are often considered the major cause of the child’s pathology (i.e. parents are the “pathogens”). • If the parents are considered incompetent and/or the home environment is viewed as impeding the success of the treatment, the child is removed from the home. 	<ul style="list-style-type: none"> • Mental illness is the result of the interaction of biological predispositions and a variety of family and environmental factors. • The smallest unit of treatment is the family system. Children’s behavior must be understood in the context of their families, and communities — including school. • Treatment is provided by mental health professionals, paraprofessionals and parents working in partnership. The family plays a central role. • Evaluation and treatment goals build on family/child strengths and competencies to change the child/family’s interactions with the most important systems in their environment. • Medications, when necessary, are used only in conjunction with information, practical assistance, support, and suggestions on ways to modify interactions within the family to promote and sustain desired changes. • Parents are partners and allies in the treatment and they have the right to make decisions for themselves and their child. • Intensive efforts are made to mobilize informal and formal resources necessary to enhance parenting and avoid having to remove children from their home and community.

Prepared by *The Family Impact Seminar*, Washington, DC. November, 1994.

Chart II

Values and Principles for the System of Care

Core Values

1. The system of care should be child centered and family focused, with the needs of the child and family dictating the types and mix of services provided.
2. The system of care should be community based, with the locus of services as well as management and decision making responsibility resting at the community level.
3. The system of care should be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

Guiding Principles

1. Children with emotional disturbances should have access to a comprehensive array of services that address the child's physical, emotional, social, and educational needs.
2. Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.
3. Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.
4. The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.
5. Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing, and coordinating services.
6. Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs.
7. Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.
8. Children with emotional disturbances should be ensured smooth transitions to the adult service system as they reach maturity.
9. The rights of children with emotional disturbances should be protected, and effective advocacy efforts for children and youth with emotional disturbances should be promoted.
10. Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.

(From Stroul and Friedman, 1986)

Chart III

Components of the System of Care

I. MENTAL HEALTH SERVICES

Nonresidential Services:

- Prevention
- Early Identification & Intervention
- Assessment
- Outpatient Treatment
- Home-Based Services
- Day Treatment
- Emergency Services

Residential Services:

- Therapeutic Foster Care
- Therapeutic Group Care
- Therapeutic Camp Services
- Independent Living Services
- Residential Treatment Services
- Crisis Residential Services
- Inpatient Hospitalization

II. SOCIAL SERVICES

- Protective Services
- Financial Assistance
- Home Aid Services
- Respite Care
- Shelter Services
- Foster Care
- Adoption

III. EDUCATIONAL SERVICES

- Assessment & Planning
- Resource Rooms
- Self-Contained Special Education
- Special Schools
- Home-Bound Instruction
- Residential Schools
- Alternative Programs

IV. HEALTH SERVICES

- Health Education & Prevention
- Screening & Assessment
- Primary Care
- Acute Care
- Long-Term Care

V. SUBSTANCE ABUSE SERVICES

Nonresidential Services:

- Prevention
- Early Intervention
- Assessment
- Outpatient Services
- Day Treatment
- Ambulatory Detoxification
- Relapse Prevention

Residential Services:

- Residential Detoxification
- Community Residential Treatment
& Recovery Services
- Inpatient Hospitalization

VI. VOCATIONAL SERVICES

- Career Education
- Vocational Assessment
- Job Survival Skills Training
- Vocational Skills Training
- Work Experiences
- Job Finding, Placement,
& Retention Services
- Supported Employment

VII. RECREATIONAL SERVICES

- Relationships with Significant Others
- After-School Programs
- Summer Camps
- Special Recreational Projects

VIII. OPERATIONAL SERVICES

- Case Management
- Juvenile Justice Services
- Family Support & Self-Help Groups
- Advocacy
- Transportation
- Legal Services
- Volunteer Programs

(From Stroul and Friedman, 1986)

Chart IV

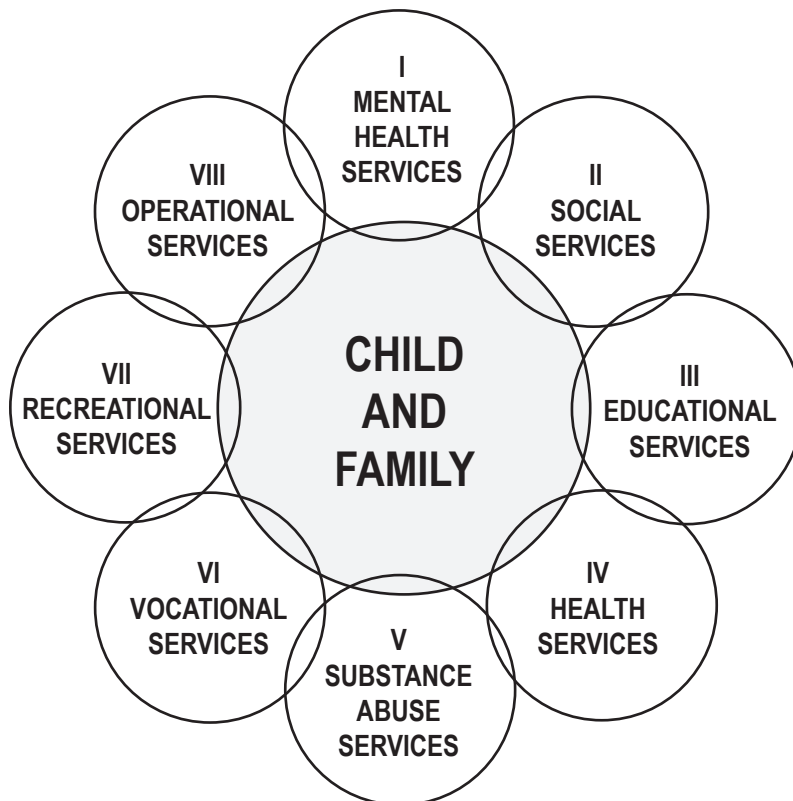
DIMENSION I: Mental Health Services

NONRESIDENTIAL SERVICES:

- Prevention
- Early Identification & Intervention
- Assessment
- Outpatient Treatment
- Home-Based Services
- Day Treatment
- Emergency Services

RESIDENTIAL SERVICES:

- Therapeutic Foster Care
- Therapeutic Group Care
- Therapeutic Camp Services
- Independent Living Services
- Residential Treatment Services
- Crisis Residential Services
- Inpatient Hospitalization



(From Stroul and Friedman, 1986)