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## ABSTRACT

The landscape for children's mental health services has changed dramatically due to the confluence of several factors. The emergence of managed care has influenced access to as well as the scope of primary care practice. Evidence-based medicine is steadily emerging and driving practice guideline development. In the rapidly changing and increasingly cost-conscious health services environment, care of children with mental health needs is shifting from mental health specialists to primary care providers. To meet these new needs, the Children's Mental Health Alliance Project was established as an interdisciplinary effort to review best practices in primary care in children's mental health; address under-recognition of mental health problems in youth; and clarify professional responsibilities across systems of care. This monograph summarizes their discussions, findings, and recommendations. Chapter 1 contains information on mental health problems in youth and the changing role of health providers. Chapter 2 concerns mental health screening. Chapter 3 discusses diagnosis of mental health disorders. Chapter 4 reviews efficacy and effectiveness. Chapter 5 reviews managed care and children's mental health. Chapter 6 discusses a systems approach. Chapter 7 presents recommendations from points of view of several participants in the field, and chapter 8 discusses issues for the future. (Contains 270 references.) (JDM)

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# Children's Mental Health: The Changing Interface Between Primary and Specialty Care

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# Children's Mental Health: The Changing Interface Between Primary and Specialty Care

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**Report of the Children's Mental  
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## Preface

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The Children's Mental Health Alliance Project emerged from conversations held among pediatricians and child and adolescent psychiatrists in 1996. At that time, we were struggling to help patients presenting with mental health symptoms in an era of rapidly shifting paradigms, reductions in resource allocations, and new payers and participants in the medical decision-making process. Across rural and urban settings, we were experiencing the same loss of familiar landmarks, and pediatric colleagues were suddenly expected to manage young patients on three to four psychotropic agents. Child psychiatrists were no longer authorized to provide therapy. Treatment guidelines were absent. The impact on children and families was undetermined. Yet there seemed to be little acknowledgment of this dramatic and sudden shift.

The landscape for children's mental health services has changed dramatically due to the confluence of several factors. Biological psychiatry and the increased use of psychotropic medicines have made tremendous advances. The emergence of managed care has influenced access as well as the scope of primary care practice. Evidence-based medicine is steadily emerging and driving practice guideline development. And, epidemiological research has documented the under-recognition of mental health problems, and resulting unmet needs, of children in primary care.

Twenty years ago, a similar effort to address the integration of mental health services in primary care took place, but on a larger scale. The goals of the 1979 Invitational Conference on the Provision of Mental Health Services in Primary Care Setting (organized by the Institute of Medicine) were to examine the benefits, disadvantages, and difficulties of linking mental health services and primary care in a coordinated approach to health care (Parron & Solomon 1979). While its goals remain relevant, dramatic changes in the field render inapplicable some of the recommendations of this auspicious meeting. Diagnoses cited have changed, the biologic underpinning of several mental illnesses is clearer, the predominant fee-for-service health care system is all but gone, and shifts in health care from the public to private sector are underway. Neighborhood health and community mental health centers which facilitated interactions between health and mental health providers are significantly reduced in number, with efforts at mental health accountability monitoring by primary care providers largely replaced by the behavioral health outcomes monitored by an external agent.

Nevertheless, today we face many of the same dilemmas as did the conferees of the 1979 conference. For example, the financing of healthcare does not support integration of mental and physical health care. Behavioral sciences training in medical schools and during residency is not commensurate with the demands of addressing mental health issues in primary care settings. We still assume that increased training of primary care practitioners is all that is needed but ought to heed words from 1979 that "experience does not support this presumption." Holistic, biopsychosocial and humanistic approaches seem as novel to us as they may have seemed twenty years ago, underscoring how little progress has been made in integration since then.

How do we reconcile all of this? The health care environment has changed so rapidly that a broad representation of health care providers was needed to identify and prioritize interventions and directions needed for provision of pediatric mental health



services for the next five years. To meet this need, the Children's Mental Health Alliance Project was established as an interdisciplinary, collaborative effort to 1) review an evidence-based, best-practices approach to the primary/specialty care relationship as it pertains to child mental health, 2) address under-recognition of and poor outcomes for the mental health problems of children and adolescents, and 3) clarify our professional responsibilities across systems of care in order to avoid duplication and to address shortages and define health service research needs. The subject of study was broad and we collectively had to achieve consensus regarding a manageable focus; we attempted to do so by limiting ourselves to systemic issues and not addressing specific disorders or their diagnosis, intervention, or treatment outcome.

In the implementation of the project, we were struck by the wisdom of our colleagues. Portions of this monograph are derived directly from their comments at the conference. Our collaborators came from across the country and brought with them their rich and diverse perspectives. We encountered an unsurpassed enthusiasm for the project and a desire to contribute expertise and time. It is important to acknowledge that there were many others who were unable to join the meeting but who made contributions through correspondence and guidance.

Implications for action and recommendations for children's mental health service research, practice, and policy for the next five years are offered at the end of this report. The field has evolved significantly during the last phase of this monograph production, and our desire to incorporate the most recent and important contributions to the literature had to be tempered by the need to present this document expeditiously to promote continued dialog and further advance the field. Similarly, omissions in referencing key citations were unavoidable and should not reflect the editors' perspectives on contributions to the field.

This monograph also summarizes what is known about managed care as it applies to children and adolescents with mental health problems. These sections are a distillation of presentations given at the Children's Mental Health Alliance Project Conference with pertinent literature citations and review inserted by the conference organizers. A complete listing of conference participants and their affiliations is attached as an appendix.

We gratefully acknowledge funding for this project provided by the Agency for Health Care Policy and Research (Grant R13 HS0913-01) and The Robert Wood Johnson Foundation (ID #032503). The following representatives of these agencies, Charlotte Mullican, Lisa Simpson and Terry Shannon from AHCP, and Tracy Orleans, Ann Pomphrey and Nancy Fishman from RWJ have been very supportive of this endeavor and participated in the content development and process of the project. Mary Jane England's incomparable energy, fund of knowledge and enthusiasm propelled us forward in the inception, Michael Jellinek's clinical competence, ongoing support, candor, and sense of humor provided us with the road map. Kelly Kelleher's insight and research were very timely and extremely helpful. It has been our privilege to work with and to learn from all of the participants of this project.

Annie Steinberg, MD  
Anne Gadowski, MD  
Michele Wilson, MD

## Executive Summary

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Children and adolescents with mental health problems are among the most underserved members of our population. With often invisible and stigmatized conditions, their needs are easily overlooked and ignored until they reach crisis stages. Over the past 20 years, the landscape for children's mental health services has changed dramatically due to the confluence of several factors: increasing psychotropic use, the emergence of managed care, advances in biologic psychiatry, and the increasing recognition of unmet mental health needs among children. In the rapidly changing and increasingly cost-conscious health services environment, care of children with mental health needs is shifting from mental health specialists to primary care providers. Thus, the primary specialty care interface for children's mental health services requires careful attention.

The health care environment has changed so rapidly that a broad representation of health care providers are needed to identify and prioritize interventions and directions needed for provision of pediatric mental health services for the next five years. To meet this need, the Children's Mental Health Alliance Project was established as an interdisciplinary, collaborative effort to 1) review the evidence-based, best-practices approach to the primary/specialty care relationship as it pertains to child mental health, 2) address under-recognition of and poor outcomes for the mental health problems of children and adolescents, and 3) clarify our professional responsibilities across systems of care in order to avoid duplication, address shortages, and define research needs. This report summarizes the discussion, findings and recommendations stemming from a conference held in November 1998 as well as a year long dialogue with experts, colleagues and families.

Establishing criteria for interaction between primary and specialty care is complicated by several issues: variable levels of background knowledge, lack of interdisciplinary means of articulating severity, lack of uniform assessment procedure for the diagnosis of these conditions, and lack of uniform understanding of what services and professional involvement are needed for children with differing levels of severity. Systems factors rather than simply clinical factors have substantial impact at present on who interacts with whom, and at what point in the child's care. Managed care organizations may limit access to specialty care and provide disincentives to out-of-network care. Alternatively, referrals to mental health specialists may be used as a substitute for limited or ineffective interaction and coordination of medical and educational systems at the community level. Behavioral health carve-outs, which provide separate contracting and incentives, often exacerbate the psyche-soma dichotomization and create incentives for the shifting of responsibility and cost. A clear and cogent plan for referral and interaction between primary and specialty care pediatric providers, regardless of the structure of the systemic organization of care, will advance the field.

Several large initiatives have emphasized the importance of prevention and early recognition of psychosocial dysfunction among children, including Bright Futures, Diagnostic and Statistical Manual for Primary Care (DSM-PC), and NIMH's proposed prevention activities. The substantial morbidity and lifelong impact associated with

mental illness warrants screening in primary care settings. Costello & Shugart (1992) state that "given...that real damage to children's lives begins at threshold levels of symptomatology, perhaps pediatric practices might be good settings for careful monitoring and for early intervention and prevention trials." However, screening for behavioral and emotional problems in childhood requires a time consuming assessment of the child, familial and environmental circumstances, an assessment deemed impractical in most primary care settings.

The current 'scorecard' on screening of children in primary care is not optimistic. Despite the recognition that the burden of illness is very high, and the reliability and validity of screening tools such as the Pediatric Symptom Checklist compares favorably to that of other medical tests, a huge gap of information remains with respect to treatment, efficacy, and the value of early intervention. The ability to mount preventive interventions and act responsibly on what is learned from the screenings is limited in most pediatric practices. While screening per se may not meet criteria for effective intervention at this point, there are changes in pediatric primary care service delivery that would improve primary care mental health services, such as increasing the continuity of care and access to mental health services for children and families. New technologies, such as telephone or in office computer-assisted interviewing, may facilitate communication between providers, patients, and family members, but the impact of these innovations requires evaluation.

Diagnostic issues include limited construct validity of diagnostic codes to describe complex psychosocial conditions, and the limited utility of diagnostic schema in terms of guiding treatment options and predicting the effectiveness of interventions. Accurate mental health diagnosis may be a function of training, motivation, practice style, and external factors, such as performance incentives. Most noteworthy, the brevity of the typical pediatric encounter limits the mental health diagnostic assessment. Pediatric patients often have sub-threshold disorders (i.e., mental health problems which cause considerable distress to parents and children, but which would not reach the level of severity specified for a psychiatric disorder according to DSM-IV). Whether early identification of behavioral symptoms at the sub-threshold level would lead to better prognosis or outcome needs to be explored.

To the extent that pediatric mental health problems are underdiagnosed, they represent the true hidden morbidity. Regardless of the method used for the screening and diagnosis of mental health problems, there needs to be a concerted effort to provide pediatric primary care providers (including physicians, nurses/nurse practitioners, social workers, school counselors, teachers, etc.) with the resources necessary to identify those patients in their practice in need of mental health services. Rost et al. provide the realistic perspective that "quality improvement efforts directed at improving detection without improving management of detected patients may not improve outcomes."

viii Outcomes data are needed to develop an evidence-based approach to what works in children's mental health service delivery. Such studies are needed to reinstate a best practices approach in the primary care/specialist relationship as it pertains to children's mental health, rather than continue to have payers and mental health professional shortages determine the frequency, level, modality and provider of mental health

services. Evidence must be gathered to compare the effectiveness of primary, specialty, and co-management models. In order to do this, a feedback loop is needed, starting with research, extracting the data, and synthesizing the data. The goal is to achieve the optimal balance of primary and specialty care for key mental health disorders in children that is based on outcomes data. Inter-disciplinary collaborative efforts are needed to conduct studies across the continuum of care.

Evidence is increasing to support the notion that delay in the detection of mental illness and initiation of mental health services leads to displaced medical utilization among adults. Pediatric psychosocial morbidity undetected early in life is also associated with displaced utilization in terms of medical visits as is parental depression, particularly maternal depression. Early increased medical care utilization and costs among children who subsequently are diagnosed with mental disorders has been documented. Thus, the timely initiation of mental health services promise to be cost-effective. However, judging the cost-effectiveness of these services will be complex because the returns on investments in child mental health should be measured as long-term outcomes, impact on other systems of care (juvenile justice, schools) and effects on other populations. Cost effectiveness studies also need to include indicators and outcomes for both parents and children, not just one or the other.

Significant health care trends for this decade include increased enrollment into managed care plans in both the private and public sector and the emergence of carve-outs. Carve-out programs place behavioral health services under specialists who are contracted to provide mental health services, usually as an independent company and under a capitated arrangement. Studies of the impact of managed care on access and quality for children with mental health problems will continue to be severely hampered by the following factors: the rapid evolution of managed care, the turn-over of managed care organizations (failures, mergers, acquisitions), and the lack of a consistent database that would allow tracking of outcomes.

Behavioral health carve-outs challenge the fundamental collaborative model of care for children and families. Carve-in models usually involve co-location of a mental health specialist in primary care settings. Access to mental health expertise in primary care settings may allow primary care providers to implement systematic screening procedures, to connect with schools and other community resources and view symptoms in a relevant context, and to more effectively refer children and families to their mental health colleagues when indicated.

The costs of the status quo are considerable—in terms of the unmet needs of children and families in the realm of mental health and development, displaced utilization that occurs in the presence of children's and families' distress, and the frustration and dissatisfaction of practitioners. The costs on the other hand of a collaborative care arrangement are mostly unknown and need to be studied. Possibilities for cost recovery in such systems include decreased displaced utilization in capitated health care systems, reorganization of office overhead expenses, increased long-term productivity and reduced morbidity. However, the increased efficiency and productivity of a logical and coordinated system of care remains theoretical and untested as few models have been evaluated. The consensus process generated several recommendations for policymakers, consumers, managers, practitioners, and researchers. These

recommendations emphasize the need for increasing parity, access, quality, and the evidence based in children's mental health services. They also call for more service integration, multidisciplinary collaboration, family involvement, and managed care accountability in the delivery of mental health services. Hopefully, the results of this project will renew efforts to create a system of care that effectively addresses mental problems of children.

## Background: Key Events in the Recent History of Children's Mental Health Services

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The following recent events have shaped the current landscape for children's mental health services.

- 1969: The Joint Commission on Mental Health of Children identified the serious lack of appropriate programs for youngsters with mental health problems. (Joint Commission 1970)
- 1975: Congress passed Public Law 94-142, Education of All Handicapped Act, also known as Individuals with Disabilities Education Act.
- 1978: Roslyn Carter brought together a group of professionals to form the President's Commission on Mental Health, Task Panel on Infants, Children and Adolescents. This Commission highlighted once again the tremendous lack of mental health services for these children.
- 1982: Funded by the Children's Defense Fund, Jane Knitzer wrote a landmark monograph, entitled *Unclaimed Children*, about the 11 million youngsters with serious mental illness, only a third of whom were receiving any treatment at all.
- 1984: Congress appropriated \$1.5 million to implement a very important piece of legislation, and started the Child and Adolescent Service System Program (CASSP). CASSP is now nationwide, organizing families and professionals around issues of serious mental illness among youth. CASSP resulted in advocacy and program principles that remain the underpinning of most of the services we provide today for children with mental illness (Burns 1996).
- 1988: The Robert Wood Johnson Foundation allocated \$20.4 million to implement the Robert Wood Johnson Foundation Mental Health Service.
- 1991: The Federation of Families for Children's Mental Health, a private grassroots advocacy organization, was developed to ensure that the voice of family members of children and adolescents with mental health problems would be heard. One of the most significant things that has occurred, not just in children's mental health but across the whole field of mental health, is the growing concern and voice of family members and recognition of the need for family involvement in the treatment of their children.
- 1992: With the help of the family movement, funding from the federal government was targeted towards children with the most serious mental illness. That program started with a budget of about \$5 million. Congress recently allocated another \$78 million to this program. Currently, forty-four sites are funded by the Center for Mental Health Services.

"If we could only integrate all the fragmented services that were being provided to these youngsters, we could really make a difference."  
*Mary Jane England,*  
*MD*

# Current Landscape

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## Prevalence of Mental Health Problems in Children and Adolescents

Children and adolescents with mental health problems are among the most underserved members of our population. With often invisible and stigmatized conditions, their needs are easily overlooked and ignored until they reach crisis stages.

Epidemiological studies demonstrate the high rate of mental health problems in children and adolescents. Yet, utilization rates for mental health services are considerably lower than expected based on prevalence rates. Community surveys (the NIMH Epidemiologic Catchment Area studies) have documented that, in some areas, two-thirds of children with psychiatric disorders and significant impairment do not receive specialist care (Leaf et al. 1996). Standardized screening of 2nd to 4th grade children in special education in one school district in Florida found that nearly half showed evidence of attention deficit hyperactivity disorder (ADHD), but only half of this number were receiving services for ADHD (Bussing et al. 1998b). Furthermore, the prevalence of mental health conditions among children and adolescents appears to be increasing. The prevalence of ADHD among children and adolescents in the United States has increased tenfold (Ferris et al. 1998). Data from the CDC show an increase in adolescent suicide rates over the past several years; 8.7% of 9th through 12th grade students have attempted suicide (CDC 1995).

From 1979 to 1996, the prevalence of psychosocial problems increased from 7% to 18% of all pediatric visits among children 4-to-15 years (Kelleher et al. 1997b). The causes, implications, and ramifications of these changing trends in the epidemiology of these disorders are poorly understood.

## Primary/Specialty Care Interface in Children's Mental Health

The Institute of Medicine defines primary care as follows:

Primary care is the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community. (Donaldson et al. 1996)

Primary care in the context of children's mental health includes practitioners in family practice, pediatrics, school-based clinics, school counselors and a variety of other practice arrangements. Many primary care providers express concern about making the right diagnosis, choosing the right treatment modality, and picking the right medication when it comes to mental health problems in children. Specialty care is needed to assist in guiding these decisions. Specialty care denotes greater expertise in diagnosis, management, and treatment. It includes psychologists, psychiatrists, and psychiatric social workers in a variety of treatment settings spanning private and public sectors. The primary/specialty care interface also includes a variety of professionals

"One in five American children and adolescents has a serious, diagnosable emotional or behavioral disorder, yet today in this country 60% of them do not receive the services that they need."  
*Nelba Chavez, PhD*

in criminal justice, foster care, schools, and daycare who have responsibility for children with mental health problems. Thus, the interface is complex, given this variety of practitioners with different training, mandates for care, and funding sources.

## **The Changing Role of the Primary Care Provider**

In the rapidly changing and increasingly cost-conscious health services environment, care of children with mental health needs is shifting from mental health specialists to primary care providers. Gatekeeping, special authorization procedures for behavioral services, and a shortage of mental health specialists have reduced access to mental health specialists. Suddenly forced to widen the scope of their practice, primary care providers are often unprepared to take on this additional responsibility. Change is taking place in the absence of a comparative analysis of the outcomes of children treated by primary care providers cf. child mental health professionals.

Mental health and the “new morbidities” are of key importance to primary care practitioners who realize that the leading causes for pediatric mortality are behavioral non-intentional injuries, suicides, and homicides (Haggerty 1973; Costello & Angold 1988; AAP 1993). Furthermore, recent studies suggest that mental health problems are of great importance to primary care providers. Child behavioral issues and ADHD were rated among the top five issues of clinical research importance in practice (DeWitt et al. 1997). Among children seen by primary care providers, 18% have psychosocial problems, and 8.5% have ADD/ADHD (Wasserman et al. 1997). Another study involving 401 clinicians from 44 states (the American Academy of Pediatrics Pediatric Research in Office Settings—PROS and Ambulatory Sentinel Practice Network—ASPN) documented that, among children being seen by primary care providers for psychosocial concerns, one-half were there for attentional problems (Kelleher et al. 1998).

Primary care providers address behavioral issues on a daily basis in well child care visits. These issues include parenting practices, discipline, warning signals, risk behaviors, and anticipatory guidance at each developmental phase. In a recent survey of more than 2000 parents with children less than three years of age, parents expressed a strong desire to obtain more guidance from pediatric clinicians regarding psychosocial issues, such as helping their children learn, effective discipline, toilet training, and sleep management (Young et al. 1998). Primary care providers are intimately involved with behavioral problems and issues on an ongoing basis and are ideally positioned at the frontline to identify and develop interventions for mental health problems.

However, primary care providers may be better at treating symptoms rather than identifying their etiology or making the diagnosis of mental illness. They are often faced with several presenting complaints but may have limited mental health diagnostic capacity. The behavioral and mental health training of primary care providers varies and does not include consistent exposure to diagnosis and treatment. There is a tremendous variability in training and exposure to updates in primary care. Furthermore, managed care pressures primary care providers to take on more specialty care issues in order to decrease referrals and control costs. Given the limits in training with these demands, fear of liability is ever present.



Primary care providers have limited office assistance in dealing with mental health issues. They are constantly faced with shortage of mental health specialists or lack of access to these specialists, particularly in rural areas. Visits are more easily terminated by writing a prescription than undertaking an on-the-spot counseling session. In addition, parents and patients are still fearful of the stigma of being labeled with mental health disease. Thus, the constraints of the primary care setting often result in the treatment of complex psychosocial symptoms and pediatric mental health problems with pharmacological interventions, rather than with a comprehensive and integrative developmental psychopathological approach.

The under-recognition and poorer outcomes of mental illness management in primary care settings has been the topic of several studies (Ormel & Tiemens 1995; Van der Brink et al. 1991; Coyne et al. 1995; Simon & VonKorff 1995); however, most of the studies have not included children or adolescents. Although recognition rates increase with dissemination of knowledge, better screening measures, and discrete diagnostic criteria, appropriate management will require training (Stoudemire 1997; Hartley et al. 1998), adherence to treatment guidelines (Tiemens 1996), pharmacologic updates, outcomes monitoring, access to specialist consultation, and office systems that facilitate mental health service delivery.

Management or treatment also varies by professional training. For example, family practitioners are less likely to prescribe medication for ADHD than pediatricians and child psychiatrists (Bernstein et al. 1997). Children who are prescribed methylphenidate by a psychiatrist are more likely to remain on medication than children seen by pediatricians or family practitioners (Miller et al. 1997). Among primary care providers seeing children for psychosocial problems, 24% received no medications, counseling or follow-up; 10% were scheduled for an additional visit; 22% received counseling only; 29% received a psychotropic medication; and 15% received both counseling and a medication (Kelleher et al. 1998). Children with ADHD in special education who were of minority background, low income, or in a health maintenance organization were less likely to be receiving services for ADHD (Bussing 1998b). Thus, significant practice variations by insurer, race, region, and discipline occur.

## **The Decade of Biological Psychiatry and Psychopharmacology**

The “decade of the brain” has witnessed increasing psychotropic use (Pincus et al. 1998) as well as multiple developments in behavioral genetics, linkages between somatic and mental health (Cohen et al. 1998), and biological psychiatry (Shore 1997; Detre & McDonald 1997; Dohrenwend 1998). These advances have shifted the focus from a biopsychosocial model to a biological model for the treatment of many mental health problems, but most notably mood disorders among adults.

Advances in psychopharmacology are occurring rapidly and at a pace that eludes most practitioners. In addition to direct consumer advertising, psychotropics are promulgated by pharmaceutical industries to primary care providers in the absence of carefully controlled trials in children and adolescents. This marketing bypasses academic detailing which would balance the pros and cons of various modalities of treatment to a greater extent and better delineate drug indications. Limited numbers of

visits under managed care also favor drug treatment as the most expedient and accessible modality available to the primary care practitioner.

Data from the National Ambulatory Medical Care Survey documented the level of stimulant and other psychotropic medication use among children. (See Table 1.) Methylphenidate production quotas have tripled and the use of methylphenidate has increased from 0.01 in 1980 to 1.4 percent in 1994 (Ferris et al. 1998). (See Figure 2.) Methylphenidate prescriptions have increased five-fold over five years (NIH 1998). Antidepressant prescriptions for children from 6 to 12 years of age increased by 43% from 1996 to 1997 (*Phila Inquirer* 1/18/98).

**Table 1. Number of Visits by Patients <18 Years Old Resulting in a Psychotropic Medication Prescription (1995 National Ambulatory Medical Care Survey)**

Drug Category	Estimated No. of Office Visits	95% Confidence Interval
Stimulants	2,069,488	1,653,964–2,485,012
SSRIs	358,616	233,344–483,888
Central Adrenergic Agonists	202,032	24,444–279,820
Anticonvulsant Mood Stabilizers	318,971	89,769–548,173
TCA's	268,770	33,946–403,594
Benzodiazepines	218,523	25,920–411,126
Antipsychotics	71,863	6,871–136,855
Lithium	63,584	15,409–111,759
Bupropion	25,069	0–53,668
Non-TCA, Non-SSRI Antidepressants	15,345	0–33,690
Buspirone	10,692	0–25,510

Based on Jensen et al. (1999)

**Figure 1. Methylphenidate Trends, 1990–95**

☛	MP production and distribution tripled
☛	Proportion of Rx's for 2–3 yr. olds doubled
☛	6% school-aged children in MD on MP
☛	2.5 fold increase in MP use in US 1990–95
☛	40% increase in outpatient visits, 1990–93
☛	27% increase in MP g/million patients, 1990–93

## Managed Care and Access to Mental Health Specialists

“We need to think about how to provide that ongoing education for parents that helps them feel...that all parents have the right to understand whether they feel okay about how things are going, that it’s okay to ask for help when they are not, and that we shouldn’t expect it only to come from our pediatrician in 13 minutes.”

*Marianne Mercugliano, MD*

With the proliferation of managed care organizations, primary care providers increasingly function as gatekeepers—often with disincentives to refer to mental health specialists. How do primary care providers balance their clinical judgment with fiduciary and gatekeeper responsibilities and decide who gets to see a specialist in a capitated system? At the present time, the most probable determinants of who sees a specialist are insurance coverage, access to specialists, and specialist availability. The 1995 AAP Periodic Survey found that a nationally representative sample of pediatricians perceive managed care as a significant factor in mental health referrals (Bocian 1997). These clinicians cited barriers including the lack of pediatric mental health specialists (62%) and financial disincentives (34%).

Historically, primary care providers had the option of referring children with mental health needs to pediatric psychologists, child psychiatrists, or other specialists. With utilization of mental health services controlled increasingly by external agents, limited by insurance coverage, or simply unavailable, primary care providers are finding themselves solely responsible for the diagnosis and treatment of many pediatric mental health disorders.

With rapid changes in the managed care and provider networks marketplace, there has been a consistent decline in the longevity of provider-patient relationships. Continuity of care, increasingly recognized as a significant determinant of the quality of care received, is threatened by changes in health plans and health insurance that can occur independent of patient or family preferences. Efforts to increase the continuity of care, i.e., increasing the probability that a patient is seen by the designated primary care provider both for well and sick visits, are likely to improve the identification and referral of mental health problems.

# Mental Health Screening of Children in Primary Care Settings

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## The Goals of Screening

Screening is “the application of a test to detect a potential disease or condition in a person who has no known signs or symptoms of that disease or condition.” (Eddy 1991) Eddy cites two purposes of screening: early detection of diseases, which may result in better opportunities for treatment, and detection of risk factors, which can be followed or changed. A good screening tool has the following characteristics: low number of false positives, low number of false negatives and the “disease” that is being screened for can be treated. An effective screening tool allows early diagnosis “at a critical point in the natural history of disease before which therapy is either effective or easier to apply than afterward.” (Sackett et al. 1985)

Screening refers not only to the identification of serious mental health problems but also to the primary prevention of mental health problems in children and their families. As outlined in health supervision guidelines by the American Academy of Pediatrics as well as Bright Futures, prevention is implemented through such means as anticipatory guidance, discussions about healthy child development, temperamental variations, discipline, and general parenting education, etc. Mental health screening is increasingly recognized as a part of primary care practice.

Behavioral disorders are the most common chronic conditions of childhood and are equivalent to asthma with regards to both cost and prevalence. There are no other conditions besides asthma that even approach their prevalence. They are costly to society, families, and children with long-term implications. The substantial morbidity associated with these disorders warrants screening.

Costello et al. state that “given...that real damage to children’s lives begins at threshold levels of symptomatology, perhaps pediatric practices might be good settings for careful monitoring and for early intervention and prevention trials.” Blackman (1992) has suggested three levels of screening: informal screening (for low-risk populations), routine formal screening (systematically implemented), and focused screening (for individuals with increased suspicion of risk).

## Screening Effectiveness

Treatment efficacy data are available for some behavioral conditions in childhood, but there is limited data on efficacy of screening. Criteria for effective screening should include evidence that earlier intervention is better.

Recently, several large initiatives have emphasized the importance of prevention and early recognition of psychosocial dysfunction, including Bright Futures, Diagnostic and Statistical Manual for Primary Care (DSM-PC), and NIMH’s proposed prevention activities. Screening for psychosocial problems has always been an important component of the pediatric office visit, from infancy through adolescence. Generally, the emphasis has been on functional assessment, with impairment based on dysfunction, and differences (not affecting functioning) viewed as developmental variations rather than psychiatric diagnostic nosology.

Probably the most critical issue is the need for earlier detection and treatment. Mental illness has lifelong impact for these youngsters and it can create a lifetime of dependency instead of a productive adulthood. *Mary Jane England, MD*

“We have to figure out how to make it possible for pediatricians and family physicians to do a good job in the realm of helping and supporting parents to do the best possible job of parenting and in identifying problems in children, parents, and families at the earliest indications.” *Ellen Perrin, MD*

Efforts such as the DSM-PC have codified the recognition of family issues and other stressors that can be addressed by the primary care provider. This should assist primary care providers in recovering compensation for the interventions, given the usual time allotted for a patient visit (average 13 minutes) and the need for additional time allocation. Other screening efforts present competing tasks to the primary care practitioner. For example, the US Preventive Services Task Force recommended 225 items primary care doctors should address in the practice of preventive medicine.

Most youth with behavioral and emotional disorders are seen in primary care settings, and infrequently in mental health specialty settings. Although clinicians do recognize many problems, the following non-clinical factors are important in their recognition as well. In addition to clinical training, the discipline of the practitioner, the setup of the office, and continuity of care (i.e., whether or not providers see their own panel of patients) are important in terms of who gets recognized. Source of history (child/adolescent or parent/caretaker) and length and type of visit (well child or acute care) may also have an impact on the likelihood that mental health problems will be recognized. The provider's interviewing style and ability to communicate also affects the mother's disclosure of psychosocial issues.

There are accurate screens that meet usual medical screening criteria for sensitivity, specificity and cost. One example is the Pediatric Symptom Checklist (PSC), a 35-item parent report symptom list developed by Dr. Michael Jellinek. These are easily scored, forced-choice items where the parents are asked to respond Never, Sometimes, or Often. Those children with a higher PSC score are 2.5 times more likely to be recognized by their provider. In one large study comparing parental PSC findings to clinician report, parents identified more psychological problems than primary care practitioners do. In this PROS and ASPN practice-based research networks study of 9,766 visits by children in primary care, practitioners did not recognize psychosocial problems for 46% of children with high scores ( $\geq 28$ ) on a parent completed Pediatric Symptom Checklist (Kelleher et al. 1997a). There was a high level of agreement between parent (PSC) and clinician for children with negative PSC. However for children with positive PSC, only 54% were identified by the clinician. This study also documented that continuity of care increases the likelihood that a primary care provider will recognize psychosocial problems in children. Thus, the best predictor of whether or not a clinician recognizes parent-reported symptoms of behavioral distress is whether or not the provider saw his/her own patient. Provider training in pediatrics, older patient age, and male gender were also important predictors of clinical recognition of child psychosocial problems.

“The primary care setting is totally appropriate as a locus of attention to the psychological issues including development in all spheres (cognitive, emotional, language, motor) as well as parental and family issues. An appropriate goal is the identification of symptoms of distress in children and in parents, as well as indications of family dysfunction. But even better would be screening for high-risk symptoms and then having the ability to mount preventive interventions. That could occur only in a system that can act responsibly on what is learned from the screenings.” *Ellen Perrin, MD*

## Barriers to Screening and Diagnosis

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Frequently mentioned barriers to addressing the mental health needs of children and adolescents in primary care include 1) the primary care provider's lack of confidence in discovering and dealing with psychosocial issues, 2) explicit or implicit judgments about the inherent value of learning about and addressing developmental and psychosocial issues in lieu of more clear cut organic conditions, and 3) the perceived acceptability of asking questions related to psychosocial functioning and the emo-

“The centrality of families in this process of screening is critical. Screening cannot be done without involving the families, whether it’s from a historical pejorative view of families to a progressive collaborative view of participating with families. Any screening approach has got to be built around what families are capable of providing in terms of information. We can enhance the capacity of families to communicate with primary care physicians through training, information, and peer to peer support.”  
*Trina Osher, MA*

tional life of children and parents. Furthermore, many primary care providers operate in an environment in which they receive little support for their investigation of psychosocial issues. These areas look forbidding and endless, and they may promise more frustration than satisfaction to a busy primary care provider. In addition to skepticism regarding the effectiveness of mental health interventions, financial and administrative barriers to care, such as referral protocols and procedures of mental health carve-outs, can result in heightened frustration regarding the lack of access and further exacerbate the problem of referral and collaboration. However, research has demonstrated that parents are not only willing but also eager to discuss their concerns about their child’s behavior and development (Young et al. 1998).

Although there are screening tools which have been shown to be feasible to administer, a simple, inexpensive screening test with sensitivity, specificity and relevance for subsequent referral or treatment has not been identified. Many believe that primary and secondary prevention requires a much broader assessment than a behavioral rating of the child, an observation of the child’s behavior, or any test that is focusing only on the child. Thus, a comprehensive assessment of the family may be most relevant. This is less of an issue for family practitioners who treat the whole family than for pediatric primary care providers, who may be perceived as not respecting boundaries.

Time is another limiting factor in the successful screening and diagnosis of mental health problems. The topics are often difficult to discuss, parents are reticent to talk about them due to their feelings of vulnerability or self-blame, and knowledge may be lacking that family problems are in the domain of pediatric care. Trust between the provider and patient needs to be established. Screening tools need to be time and cost efficient because screening, if done at all, needs to be done with all children and all families. The first consideration in the busy ambulatory setting is what will be practically feasible.

Practitioners may also be resistant to the identification of a mental health problem for a variety of reasons. There is a desire on the part of primary care physicians in general not to label children due to real or imagined parental displeasure, alterations in insurance coverage, and social stigma. The Diagnostic and Statistical Manual–Primary Care (DSM-PC) was developed to provide non-psychiatric and, presumably, less threatening diagnostic nomenclature for physicians to use. But recognizing problems is also affected by the prevalent sentiment that interventions are either inaccessible or ineffective. To date, there is little efficacy research demonstrating the impact of primary prevention on the development of mental health problems in children.

The feasibility of implementation of mental health screening in a busy primary care office or clinic poses another obstacle. In one study of 400 primary care offices without research assistants or training (except a 3-minute video tape which costs only several dollars to deliver to each setting), completion rates of 95% on 20,000 visits to primary care doctors were reported (Jellinek et al. 1999). Scores were internally consistent and there were few differences in completion rates across race, ethnicity, or income. Regardless of the population, screening appears feasible to implement in pediatric primary care if considered worthwhile.

What happens when the results of screening instruments are shared with primary care practitioners? In studies of adult depression screening, practice behavior did not change because clinicians did not know how to use the information obtained. Similarly, having access to the results of pediatric checklists may not change post-screening pediatric practice because practitioners are not sure how to interpret the data, don't have adequate time, and/or don't have necessary resources (Cheng et al. 1996). Even with a taxonomy/format most appropriate for primary care, the recognition of a behavioral/emotional problem in 4–8 year old children was associated with no behavioral intervention in 31% of cases and referral to specialty services in only 16%. (Horwitz 1992). Demonstrating the efficacy of screening requires not only a short, accessible, and meaningful tool, but also feedback and guidance for the practitioner, with recommendations that are contextually relevant.

There is limited literature that addresses provider knowledge, attitudes, or beliefs about screening instruments and their validity and utility in the practice of pediatric care (Cheng et al. 1996). Some clinicians and researchers fear that, in the absence of effective treatment, a screening tool can lead to inappropriate interventions. Screening tools should always be followed by a clinical assessment of the symptom, preferably in an ecological context and with family and school staff who know the child best. Screening for behavioral and emotional problems in childhood must include an understanding of the adverse circumstances that pose great risk to children, although many factors, such as homelessness, may not be easily altered by the primary care provider.

Screening encompasses a broad array of psychosocial issues, including behavioral, developmental, and adolescent adjustment issues, in addition to purely psychiatric disorders. A central challenge is to achieve a level of standardization in primary care practices that leads to effective screening, diagnosis, and management. Standardized instruments, not just for screening but for family feedback and discussion, would facilitate communication between families and patients. In one study, 8,000 of 20,000 children were labeled by the primary care doctor as needing assistance. The vast majority of those families were satisfied with the services their primary care doctor provided, regardless of the number of behavioral symptoms present (Kelleher 1999). All of the families expressed their need to talk more with their provider.

The current 'scorecard' on screening is that despite the recognition that the burden of illness is very high, despite the fact that screening performance is pretty good compared to most other medical tests, there remains a huge gap of information with respect to treatment, efficacy, and the value of early intervention. Prior literature has documented that the characteristics of the practice, the provider, the parent, and the type of problem all influence recognition of mental health problems. So while screening per se may not meet criteria for effective intervention at this point, there are some things that pediatric primary care providers can do to make primary care mental health services better, such as improving the continuity of care.

"In an optimal primary care multidisciplinary environment, problems would be managed by prompt referral and ongoing co-management by mental health providers who are readily available to provide responsive care for children and families. However, we know now that a lot of the optimal detection doesn't work." *Dennis Drotar, PhD*

"If we ask physicians to do a blood count in their lab with a microscope, they wouldn't do it, but when we hand them the results of a hematocrit done on a Coulter counter, they all know exactly what to do with it. I think we need to move in that direction with behavioral screening too." *Kelly Kelleher, MD*

“A significant challenge limiting effective identification and management of children’s mental health problems is the family’s understanding of the child’s difficulties.”  
Kelly Kelleher, MD

## **Screening Parents of Children Seen in Primary Care Settings**

The pediatric field of vision has expanded from children’s physical health to include developmental progress, emotional progress, and school success. Pediatrics has also broadened its range from children to families to schools and to communities. While in the 1980s the focus in pediatrics was on the new morbidity and the mental health issues of children, and this area then became a legitimate part of pediatrics. In the 1990s, the new focus of attention is on parents’ mental health issues and struggling to figure out if and how this issue can legitimately become a part of pediatric care.

Winnicott once noted, “There is no baby without the mother.” When we are dealing with young children, detecting and referring significant disorders includes detecting problems that occur within the family that may have a significant impact on the child, e.g., maternal depression, domestic violence, or substance abuse. Mental health screening of parents whose children are seen in primary care settings is a non-issue for family practitioners—their identified patient is the entire family, and screening all members is routine practice. In one recent survey, 80% of family physicians reported that they use screening instruments regularly (Sansone, Wiederman & Sansone 1998). Screening for domestic violence and post-partum depression are also recommended.

Screening can be as brief as asking mothers how they are doing, or as complete as using questionnaires, such as the Edinburgh Postnatal Depression Scales and the Postpartum Depression Inventory Checklist. (*AAP News*, August 1998; 14 (8):6.)

Behavioral problems are complex, but it is particularly difficult for parents to confront their child’s behavioral or emotional problems. The issue of stigma in family and communities should also not be overlooked. Professionals may have contributed to this denial with their theories of child development in which parents were held accountable. Furthermore, in this biological era, parents are still viewed as the problem in terms of etiology. Conscientious pediatricians face these obstacles when they talk with parents about what to do next.



# Diagnosis of Mental Health Disorders in Primary Care

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## Defining Psychiatric Disorder

The first question in the study of diagnosis in child mental health regards the definition of a child psychiatric disorder. As Angold and Costello (1993) have pointed out, "the most vexing problem concerns the definition of 'morbid' conditions in childhood and adolescence." Cantwell (1988) offers the following definition: "[a] problem in behavior, emotions, relationships, or cognition that is of sufficient severity and duration to cause distress, disability, or disadvantage." Of course, the definition of "sufficient" is subject to remarkable variability and is not always easy to define in light of the high prevalence of milder behavioral disorders encountered in general practice.

"...definitions of mental disorders work least well in delineating the boundary between normality and pathology.....this boundary is likely to vary greatly from culture to culture, and the definition is also likely to depend on the availability of practitioners to treat the disorders that have been defined." (*Frances et al. 1994*)

In addition to the definition of psychiatric disorder, the diagnostic process has been described as an important intervention whose aims, as described by Cantwell (1998) are to determine:

- Is there a psychiatric disorder present?
- If there is a disorder, do the symptoms fit into a recognized clinical syndrome?
- What forces are maintaining the problem?
- What forces are facilitating the child's normal development?
- What are the strengths and competencies of the child and of the family?
- Untreated, what is the likely outcome of the child's disorder(s)?
- Is intervention necessary?
- What types of intervention are most likely to be effective?

The validity of a psychiatric disorder often can be best viewed retrospectively, in the context of the history, course of illness, and response to treatment. The diagnostic process is important in its capacity to incorporate context-relevant information. Its aims, as described by Cantwell, include not only the determination of whether or not a psychiatric disorder is present, but also the forces maintaining the problem. It also includes assessment of the factors facilitating the child's normal development, the strengths and competencies of the child and of the family, the likely outcome of the child's untreated disorder(s), and the necessity and efficacy of interventions.

The prevalence of psychiatric disorders encountered by pediatric primary care providers determines the degree to which increased surveillance and identification is merited. Costello et al. (1998) found the prevalence of DSM-III-R diagnoses in patients ages 7–to–11 to be 22%. Garralda and Bailey (1986, in several GP practices in Manchester, England, found the prevalence of psychiatric disorders in pediatric patients to be 23%. These figures are not disparate from several community studies of the prevalence of pediatric mental disorder of 18 to 26%. Bird et al. (1988) in Puerto Rico, found the prevalence of DSM-III diagnoses to be 49%, but when their rating on the children's global assessment scale was taken into account, the prevalence dropped to 18%. Thus, using good assessment measures, several studies have found that roughly

one in five children attending pediatrician practices have significant mental health problems.

## Diagnostic Tools

Large practice panels, time constraints, and the absence of available consultation resources leave many primary care providers unable to devote adequate time to conducting indepth diagnostic evaluations or psychotherapy.

DSM-IV addresses the multiaxial classification system. However, the emphasis of the manual is on the categorical listing of diagnoses, and physicians and other clinicians have the option of not using the multiaxial coding. Other multiaxial systems have been proposed for pediatrics, such as the ICD-8 multiaxial classification of mental disorders in childhood, which proposed six axes:

- Clinical psychiatric antidromes
- Specific disorder of psychological development
- Intellectual level
- Medical conditions
- Associated abnormal psychosocial situations
- Global assessment of psychosocial disability

In an effort to create a more prevention-oriented, developmentally-based system for classifying psychosocial diagnoses of children and adolescents in primary care within mental health systems (Wolraich et al. 1996), the DSM-PC was developed as a symptom-oriented manual designed to conform to DSM-IV diagnostic classification specifications. It considers different manifestations of symptoms based on the age of the child and attempts to move beyond the false dichotomization of environmental influence and innate biological factors. Both merit equal recognition and mandate intervention when identified. The acceptability, reliability, and utility of the DSM-PC is as yet unknown.

Costello and Shugart (1992), using data from the Pittsburgh HMO prevalence study, found that pediatricians identified only 13% of the children given clinical DSM-III-R diagnoses. Garralda and Bailey (1986) found that, in children ages 7-to-12, 22% were identified by parental questionnaire as deviant; only 1% of parents had a chief presenting complaint of mental disorder, and only 1% had behavioral concerns as the second reason for attendance. Lavigne et al. (1993), in a study of the presence of emotional/behavioral disorders in preschool children, found that pediatricians identified 8.7% of children as compared to 14.7% identified by psychologists. Using the Pediatric Symptom Checklist, Kelleher et al. noted that only 54% of the patients with elevated PSC scores by parental report were identified by the clinicians to have psychosocial problems (Kelleher 1997a). Sharp et al. (1992) found that even when the psychosocial problems were elicited as part of well child visits, physicians responded with information, reassurance, guidance, or referral in only 40% of cases.

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Pediatric patients often have sub-threshold disorders (i.e., mental health problems which cause considerable distress to parents and children, but which would not reach the level of severity specified for a psychiatric disorder according to DSM-IV). Costello and Shugart (1992) looked at the prevalence of sub-threshold disorder as defined by more inclusive criteria on Diagnostic Interview Schedule for Children (DISC). They found that, in addition to the 22% with DSM-III-R diagnoses, 40% of children had sub-threshold disorders. For externalizing disorders, even sub-threshold disorders

“I spent six weeks going to class to learn about delivering my baby which turned out to be about 30 minutes in the course of his life. I spent six hours learning how to breast feed my baby, which took about a year of his life. After that, no one ever made it sound as though I should actively get any information about the next 18 years of his life. I have more information when I buy a toaster oven about what to do with it subsequently. For the rest of my child’s life those intermittent 13-minute visits with the pediatrician are supposed to somehow provide me with all of the subsequent anticipatory guidance that I need to understand whether things are okay in my family, whether they’re nurturing enough for my child, whether my child is different in some way, whether I should seek help!”

*Marianne Mercugliano, MD*

were associated with significant impairment. Extending their correlational analyses longitudinally, threshold level diagnoses were found to carry a poor prognosis Five years later when accompanied by earlier functional impairment (Costello 1999). Whether early identification of behavioral symptoms at the sub-threshold level would lead to better prognosis or outcome needs to be explored further.

The diagnostic process in DSM-IV has also been criticized for focusing on the classification of the psychopathology of the child rather than the psychosocial situation and life events on behavior. Environmental factors often play key etiological roles in the development and maintenance of child behavioral disorder. In addition, there is evidence that intervention aimed at improving parent discipline can improve child adjustment. Inclusion of factors such as relational problems has been limited by uniform assessment measures for primary care settings.

Behavior rating scales, such as the Child Behavior Checklist (CBCL) or the Behavior Assessment System for Children (BASC), are useful in identification of a wide array of symptoms, and the computer interpretation is useful in comparing the severity of these symptoms to those of other children of the child's sex and gender. Kasius et al. (1997) tested the convergence between the CBCL and the NIMH-Diagnostic Interview Schedule for Children (version 2.3) among children referred to a mental health clinic and found that there was a convergence between the different subscales and related DISC-2.3 diagnoses. In a recent comparison of checklist scores from psychiatric structured clinical interviews, Jensen cautioned that there is a need for better discrimination of diagnostic subtypes and cross-validating information of sources and assessment methods is essential given our limited knowledge base (Jensen & Watanabe 1999).

Self-report questionnaires, such as the Children's Depression Inventory (CDI), the Revised Children's Manifest Anxiety Scale (RCMAS), and the Youth Self Report (YSR), provide information on current symptoms but do not parallel diagnostic criteria, and sensitivity may be too low for these to be used alone diagnostically. Also, onset and duration of symptoms are not elicited, and the degree of comorbidity in pediatric mental disorders means that the clinician needs to consider the child's mental state in more than one domain of psychiatric dysfunction. Instruments such as diagnostic structured interviews are designed to assess multiple psychiatric domains. From Hodges' review (1993) of the use of these instruments, children and adolescents can answer direct questions regarding their mental state without adverse effects. Parent and child agreement varies, with more agreement for behavioral symptoms, moderate agreement for depression symptoms, and poor agreement for anxiety. Psychiatric expertise is not needed to administer the interview, but training is required. In addition to diagnosis, the level of impairment needs to be included in order to assess the need for intervention and level of intervention. In all of these questionnaires and interviews, the emphasis is on symptomatic or behavioral presentation, rather than functional status.

### Computerized Assessment

Regarding screening and diagnosis, there may be lessons to learn from the adult primary care experience with computerized screening and assessment and management of mental health problems, use of interactive voice response technology (touch-tone telephone) (Mundt 1998), and number of questions needed to screen for depression (Whooley et al. 1997). For example, a recent study compared diagnosis by telephone-assisted computer-administered version of PRIME-MD to those made by a mental health professional. Prevalence rates, sensitivity, and specificity were similar; however, patients reported twice as much alcohol abuse on computer. This method was

“We need to expand our paradigm here into much broader tasks. It is not only pediatricians but also insurers, families, and professionals who are involved in this process. I think the issue of working wherever we can to enhance consumer participation in this process and understanding of their child's problem is very important. We need to develop more organized approaches in which we are working with our pediatric colleagues to enhance screening, detection, and management at the same time. Collaborative practices are still the wave of the future. We don't know how these practices really work. We need to do a better job of not only making them work but also analyzing outcomes.” *Dennis Drotar, PhD*

concluded to be "a valid instrument for assessing psychopathology in primary care patients." (Kobak et al. 1997) Applications of these technologies in pediatric practice have yet to be evaluated.

To further save health personnel time and to be able to address the mental health needs of a wider population, the use of computers in self-administered structured interviews has been considered. Weissman et al. (1998) have studied the identification of mental health symptoms using the Symptom Driven Diagnostic System for Primary Care (SDDS-PC) in this computerized format. The system was acceptable to the primary care physicians who were able to use the information obtained to make mental health diagnoses. The system uncovered previously unrecognized cases and frequently led to the physician's review of symptoms with the patient. Mental disorders detected by the system were significantly associated with patient functional impairment. Although such a computerized system has not been tested in children, a version of the DISC-4 (NIMH-DISC-IV-Voice) is planned.

While it is not clear that additional routine mental health screening is indicated in primary care pediatric practice, an exploration of the efficacy of new technologies, such as touch-screen computers, which may facilitate communication of the results to providers, patients, and family members, is warranted.

## Collaboration and Referral

Pediatric primary care providers need help to create a context and opportunity for parents, children, and adolescents to discuss their concerns and difficulties; this may be best done in collaboration with another colleague in the ambulatory care setting. Efforts to enhance the acceptability of interventions, ranging from psychotherapy to medication, include using videotaped preparation materials to provide information, demystify the process, and debunk myths for family, children, and adolescents.

If consensus can be obtained, a clear and cogent plan for referral and interaction between primary and specialty care pediatric providers would help to advance the field. For example, attention deficit hyperactivity disorder (ADHD) is one of the most common problems that presents to pediatric primary care providers, neurologists, and mental health professionals. Despite the prevalence of this problem, there is still an absence of an appropriate public health response to ADHD. There is no consistent approach to its diagnosis and management, education of parents, or training of professionals in its detection and management. The child may be seen by providers of many different disciplinary backgrounds, and the sources of referral may include teachers and school staff who may have very different ideas about a needed treatment plan. Children with ADHD may be better served by creating an interdisciplinary consortium and single point of contact with a parent-advisor. Experience managing more than 300 families with a child with ADHD or other problems at one center has revealed increased parental and provider satisfaction with the referral process. (Drotar & Zagorski in press)

18 By providing immediate access to information and support, efficiency of and improved access to care with the most appropriate providers can result from even modest efforts to coordinate care. Terry Stancin at Cleveland Metro Health Medical Center has developed a coordinated approach with pediatricians in her setting. Using a selective screening process with children who present with behavioral problems (often ADHD), children and their families are administered screening assessment instruments on site. A report is generated and the families receive feedback. The providers are also given standardized information regarding possible interventions and referral sources that can be used immediately with families.

Carve-outs challenge the fundamental collaborative model of care for children and families, and the advantage they offer to appropriate screening and diagnosis. Having a partner with mental health expertise in a primary care setting allows primary care providers to identify and focus on children at special risk, to implement systematic screening procedures, to connect with schools and other community resources, to view symptoms in a relevant context, and to refer children and families more effectively to their mental health colleagues when indicated.

If primary care providers are to play a significant role in the diagnostic process, education regarding that process needs to be provided and billable time needs to be allotted. Identification entails a certain degree of responsibility and liability. Therefore, increased identification of mental disorders or significant behavioral symptoms also means that the provider will need to have readily available information regarding next steps, including accessible behavioral health referral sources and direct consultation with specialists who can aid in the referral process.

In addition, some provision to provide mental health services for sub-threshold symptoms as well as for psychosocial and relational issues not associated with an identified psychiatric disorder should be considered. Many of these services could be provided by the pediatric primary care provider if appropriate guidelines and training were easily available, or by an identified mental health professional affiliated with or located within the practice setting.

Largely under-utilized resources available to the pediatric primary care provider include school staff such as school psychologists, social workers, counselors, nurses, and teachers. Parents, parent support organizations and community members can also provide invaluable assistance with improving both screening and diagnosis; these individuals may serve as informal resources to the child's family or, more optimally, become staff and trained paraprofessionals in the pediatric practice and enhance the capacities of families to participate in both the screening and diagnosis of mental health problems in childhood and adolescence.

It is important to highlight some of the training issues. More education about child development and about child and family mental health is needed at all levels, e.g., for residents in pediatrics and in family medicine at the medical school level, for nurses and nurse practitioners through various CME media. The content and context of the education needs to reflect what it is that we'll be expecting pediatric and primary care providers to be doing in their offices.

To the extent that pediatric mental health problems are underdiagnosed, they represent the true hidden morbidity. Regardless of what methods are used for the screening and diagnosis of mental health problems, there needs to be a concerted effort to provide pediatric primary care providers (including physicians, nurses/nurse practitioners, social workers, school counselors, and teachers) with the resources necessary to identify those patients in their practice in need of mental health services.

“Our training programs need to be adapted so that they also are collaborative and address the barriers and the benefits and the possible divisions of responsibilities in the context of a collegial relationship.” *Ellen Perrin, MD*

# Efficacy and Effectiveness

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## Efficacy Data

**Psychotropic Medication—Efficacy Trials.** There are clearly increasing prescribing patterns. In many instances, when a child reaches the tertiary care center, they have been through every other treatment. Clinicians often start with behavioral and family therapies. The child is still suffering. It is difficult to do studies on these children. Industry does not want to do these studies because of liability. Yet, extrapolation of adult data is not always valid for safety and efficacy.

Despite the lack of data on the outcomes of treatment with many psychotropic medicines among children, pediatric use is on the increase (Vitiello and Jensen 1997). Among children, 75-80% of psychotropic medication is prescribed off-label despite the fact that extrapolation of adult data is not always valid for safety and efficacy for these medicines among children.

“I am troubled by people throwing out ideas without data because there is a lot of stigma and bias that runs in all kinds of directions, anti-medication, pro-medication. So, in God we trust, but from all others, demand data.”  
*Peter Jensen, MD*

The safety and efficacy of the use of several psychotropic agents in children are yet to be documented, however several studies are underway. The NIMH, in concert with the National Plan for Research on Child and Adolescent Mental Disorders, has identified pediatric psychopharmacology as being a highly important, yet understudied, area of research. The Presumption of Inclusion of Children in NIH Studies (effective Oct 2, 1998) should increase efficacy research. Networks of research units focused on pediatric psycho-pharmacology have been established by the NICHD and the NIMH. However, methodological, ethical, legal, regulatory, financial, and family/community issues present formidable challenges to the conduct of needed psychopharmacological research. Difficulties conducting studies with children include parental concerns, urgency and lack of developmental outcome measures and research tools. In addition, the FDA Pediatric Labeling Initiative should improve the drug information provided to prescribers.

**Psychotropic Medication—Studies in Clinical Settings.** Table 2 describes the current level of evidence for medication efficacy among children. An ABC ranking is used. A means that there are two or more well-controlled, well-powered studies showing that it is efficacious; B means that there are 1 or more; and C means case reports or open trials. Except for stimulants, all of the long-term efficacy is in the C category. For certain conditions, such as ADHD and OCD (obsessive-compulsive disorder), there is ample data to suggest that medication provides continued benefit with sustained treatments (>6 months). Of course, compliance, acceptance and palatability issues modify these outcomes in real life settings. For example, in the Multimodal treatment studies, half of the people invited to participate in the trial refused. Of those who refused, half did so because they did not want medication and the other half because they did not want psychosocial treatments.

**Table 2. Scientific Knowledge in Pediatric Psychopharmacology vs. Frequency of Usage: A Mismatch? (Based on Jensen 1999)**

		Level of Supporting Data				Estimated Frequency of Use	
Category	Indication	Short-term efficacy	Long-term efficacy	Short-term safety	Long-term safety	Rank in Descending order (NAMCS)	Rank in Descending order (IMS)
Stimulants	AD/HD	A	B	A	A	1	1
SSRIs	• Major depression	B	C	A	C	2	2
	• OCD	A	C	A	C		
	• Anxiety disorders	C	C	C	C		
Central Adrenergic Agonists	• Tourette disorder	B	C	B	C	3	4
	• ADHD	C	C	C	C		
Valproate and Carbamazepin	• Bipolar disorders	C	C	A°	A°	4	7
	• Aggressive conduct	C	C	A	A°		
TCAs	• Major depression	C	C	B	B	5	3
	• ADHD	B	C	B	B		
Benzodiazepines	• Anxiety disorders	C	C	C	C	6	6
Antipsychotics	• Childhood schizophrenia & psychoses	B	C	C	B	7	5
	• Tourette disorder	A	C	B	B		
Lithium	• Bipolar disorders	B	C	B	C	8	8
	• Aggressive conduct	B	C	C	C		

° Safety data based on studies of children with seizure disorder

A = adequate data to inform prescribing practices; for efficacy and short-term safety: ≥2 randomized controlled trials (RCTs) in youth; for long-term safety: epidemiologic evidence and/or minimal adverse incident report to FDA

B = for efficacy and short-term safety: 1RCT in youth or mixed results from ≥2 RCTs; for long-term safety: sporadic and anecdotal reports of adverse events, suggesting rare side effects of clinical significance

C = for efficacy and short-term safety: non-randomized trial data or anecdotal case reports or opinion in youth or controlled data in adults; for long-term safety: minimal or no data

Based on Jensen et al. (1999)

**Psychotherapy.** Four meta-analyses of >300 treatment outcome studies demonstrated effect sizes that range from 0.71 to 0.84 (Weisz et al. 1987; Weiss et al. 1995). These analyses suggest “medium” effects of psychotherapy among adults. Among children, there are nine studies that compare care in clinical settings versus research settings, in which the effect sizes range from -0.40 to +0.29 with a mean effect size of 0.01 (Weisz et al. 1995).

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The APA Clinical Psychology Division has recently completed a major review of its psychosocial treatments. They applied two sets of criteria: “well-established treatments” and “probably efficacious treatments.” A “well-established treatment” is defined as a treatment for which there have been at least two well controlled studies with appropriate power, random assignment, or nine single-case studies. The studies had to be manualized, to specify the patient population and had to have been repli-

cated independently. Probably efficacious treatment refers to those treatments for which two studies have shown the target treatment is more effective than a wait list control or one study that met the criteria for well-established or three single-case studies. They also required manualization, they required the specification of the client sample but didn't require independent replication.

In the realm of psychosocial treatment, there are well-established treatments for anxiety disorders. Those treatments are operant conditioning, involving walking the patient through a graded exposure followed by praise or reward, and participant modeling. "Probably efficacious treatments for anxiety disorder are systemic desensitization, modeling (or "vicarious conditioning"), and CBT including the coping cat methodology. Kendall et al. (1997) have shown that when the Coping Cat is added to a family anxiety intervention (FAMT, developed by Barrett (1998) it is effective and the gains persist for over a year.

In the realm of treatments for ADHD, clearly medications are effective. Looking at behavioral treatments for ADHD, there are well-established treatments that reduce the symptoms in the child. These treatments are behavioral parent training and behavioral classroom interventions. At this point, there is no evidence for effectiveness for family therapy, individual therapy, or cognitive therapy.

In terms of conduct disorders, there are both well-established treatments and probably efficacious treatments. In the well-established category are the parent training developed by Patterson and Gullion and the adaptations using videotapes done by Webster-Stratton (1984).

**Combinations of Psychotherapy and Pharmacotherapy.** Large-scale clinical trials have the power to get at questions of mediators and moderators and what works best for whom. Multi-site trials also achieve generalizability across settings. At NIMH, there are a number of large scale trials going on that are in various stages. For example, the Multimodal Treatment of ADHD (MTA) is a large study comparing medication, a very intensive psychosocial treatment, combined treatment both together and referral back to the community. The study is following 576 children, randomly assigned, for an average of 14 months.

**Research Needs.** The ingredients needed for combined treatment studies include manualized treatments, treatment algorithms, and shared expertise within and across sites. The mediators of outcomes, such as comorbidity or socioeconomic status, require testing and description. Studies of family engagement and choice are also needed, as these are likely to be important mediators as well. As the section on outcomes will detail, the range of outcome assessments requires expansion beyond symptoms to function and quality measures. Beyond efficacy trials, real-world settings need to be compared with research treatments in order to account for differences in outcomes. Thus, a new genre of research is needed to take empirically supported treatments into clinical settings and to study how to make them work. Specifically, we need to know what is feasible, palatable, sustainable, and affordable. Such studies should include how treatment processes and quality improvements approximate practice guidelines and what impact these processes and guidelines have on outcomes.

## Evidence-Based Medicine and Mental Health

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The rationale for evidence-based medicine is to improve the quality of care, to enhance treatment effectiveness, and to reduce costs of treatment primarily through reducing the use of ineffective treatments. The general goals of evidence-based medicine are:



- to promote the use of evidence-based medicine
- to generate evidence of efficacy and effectiveness where it is lacking
- to determine what practices are most likely to provide good outcomes

In order to do this, a feedback loop of research, extracting data, and synthesizing data is needed. Psychiatric research networks have been developed in order to take research from the tertiary care centers into the clinical settings, where patients actually are. Of all the children with ADHD, the vast majority are seen in primary care, and only about 20% are being seen by psychiatrists (Zarin 1998). About 50% of the patients seen by child psychiatrists have ADHD. The characteristics of these children are that most are male, 58% were 10-14 years old, and about 70% had more than the one diagnosis other than ADHD. In terms of school performance, 36% were in special education, and 13% had repeated a grade. A Global Assessment of Function (GAF) rating showed that most of them were in the moderate to some difficulty range. About 30% of the time, these children were identified by a family member; about a third of the time, it was school personnel; and a non-psychiatric physician identified them "not very often." The conclusion of these studies was that psychiatrists really are seeing a more complex group of children. We do not have clinical trials to support the treatment of children with multiple comorbidities who seem to be requiring multiple kinds of treatment modalities. One of the policy questions is, "How can we get that kind of data to help guide the treatment for these kinds of children?"

"Who is going to spend time with kids to develop the relationships with them that we need to and/or support healthy relationships-making, whether it is in their schools, in their neighborhoods, or in their families? Medications work to the extent to which they make children more malleable, responsive to the environment, but if that environment itself remains unchanged, we have seen again and again that medications fall far short." *Tony Rostain, MD*

## Diagnostic and Treatment Guidelines

Studies of adults with psychological disorders detected by primary care practitioners have documented that recognition is a necessary but not sufficient condition for delivery of treatment (Tiemens et al. 1996). Thus, primary care practitioners need training not only in recognition, but also in treatment of mental health problems. Although an evidence-based approach would appear to be the best way to standardize care and redirect the practitioner's attention to outcomes, the evidence supporting one treatment modality over another for children's mental health services is often missing. Currently, there are no practice parameters issued by the AAP regarding mental health problems, although practice parameters for ADHD are expected within one year. In addition, there is no cogent, strategic plan for the optimal integration of primary and specialty care service delivery for youths.

## Measuring Outcomes

Outcomes data are needed to develop an evidence-based approach to what works in children's mental health service delivery. Such studies are needed to delineate a best practices approach in the primary care/specialist relationship as it pertains to children's mental health, rather than continue to have payers and mental health professional shortages determine the frequency, level, and provider of mental health services. In order to do this, evidence must be gathered to compare the effectiveness of primary, specialty, and co-management models. The goal is to achieve the optimal balance of primary and specialty care for key mental health disorders in children that is based on outcomes data. Inter-disciplinary collaborative efforts are needed to conduct studies across the continuum of care.

Development of appropriate outcome measures is a critical first step in this process. Given that the rate of psychological diagnosis peaks during early elementary school and early adolescence (Schor 1986), mental health outcomes must be developmen-

tally appropriate (Forrest et al. 1997). These measures must also effectively integrate information from multiple contexts and sources, including the child, parents, teachers, and health care professionals (Offord et al. 1996). As mental health outcomes for children are being developed, further steps must be taken to translate these outcomes into measures that can be used in clinical practice.

Additionally, outcomes must be related to processes of care and treatment. Although several advances have been made in measuring childhood behavior and functioning, including symptoms, impairment, social competence, and emotional regulation, these assessments are seldom linked with other kinds of outcomes. Few studies define outcomes beyond mere symptom reduction. Few studies investigate the effectiveness of psychotherapy outside of research settings.

Models for measuring mental health outcomes for children and adolescents are being developed (Hoagwood et al. 1996b; Jensen 1996b). Hoagwood et al. (1996) suggest that the context of any impact to be assessed must receive more and more attention. They call for more studies that examine the impact of what, for whom, under what circumstances and in relationship to what goal. They recommend a dynamic and interactional model of outcomes. The model is composed of five domains—symptoms and diagnoses, functioning, consumer perspectives, environments, and systems.

Symptoms are any of the emotional or behavioral symptoms a child may exhibit in one or more settings. Functioning refers to the ability of children to adapt to varying demands of home, school, peer group, or neighborhood. Functioning is on a continuum; at one end are competencies; at the other, impairments. Consumer perspectives encompass the subjective experience of the consumer and include assessment of the child or family's quality of life, their satisfaction with care, and the impact, burden, or strain on the family as a result of the child's symptoms and impairments. Environmental outcomes refer to features of the child's primary settings that are amenable to intervention. Systems outcomes include two sub-types: service-related and organizational/cost-related. Service outcomes refer to the level, type, duration and change in service utilization or availability. Systems outcomes also include assessments of the relationships between or among service organizations and evaluations of the costs of services.

Jensen, Hoagwood, and Petti (1996a) provide an incisive review of the literature regarding behavioral health care outcomes, using the dynamic and interactional model introduced above. In particular, they evaluate the literature focused upon specific treatments for the following specific disorders: disruptive behavior disorders, attention-deficit/hyperactivity disorder, anxiety disorders, affective disorders, autistic disorders, eating disorders, and other disorders. Jensen et al. also examined variability in outcomes as a function of varying settings (e.g., inpatient cf. outpatient cf. day). They provide a summary of studies assessing the impact of services of the following types and settings: outpatient, family preservation, therapeutic foster care, day treatment, intensive case management, family support, and inpatient hospitalization. They also evaluate research regarding systems of care. They note a widening gap between research and clinical practice. They assert that three areas of prospective research are particularly promising: 1) studies that investigate the differential long-term effects of various treatment alternatives for children with specific clinical disorders; 2) studies that package multi-faceted treatments and export them into naturalistic settings where they can be incorporated into routine practices; and 3) studies that examine and incorporate consumer perspectives (e.g., satisfaction with treatment, quality of life, and impact of a child's illness on the family) with other outcome assessments.

In regard to the research base, Hoagwood et al. (1996) indicate that the child behavioral health literature lags behind the adult behavioral health literature. Few studies

link the outcomes of treatment approaches to specific disorders. Controlled studies that offer clear indications for treating specific conditions are few in number, and most of the uncontrolled studies are methodologically weak. Outcomes are not often assessed comprehensively in accordance with the model advanced by Hoagwood et al. (1996). Length of follow-up is typically quite brief (often 4-to-6 weeks).

## Quality Indicators

Salzer et al. (1997) state that the importance of evaluating quality is heightened by predictions that the current basis for competition among managed care companies, i.e., the cost of services, will level off, resulting in managed care organizations competing on the basis of judged quality of service.

Bickman and Salzer (1997) speak to the need for expert evaluators to help ensure the delivery of high quality mental health services. They refer to “the trinity of quality,” calling for a linkage of structural, process, and outcomes-focused measures to develop a valid approach to quality measurement. Identification of quality indicators with criterion-related validity is needed. Outcomes and outcome indicators need to be related to structure and process indicators. They also assert that assessment of quality based solely on the measurement of outcome is flawed if there is no documented relation between outcome and the aspects of care that contributed to these outcomes. They contend that quality is best assessed by focusing on the care delivered rather than outcomes. At the time of their paper, they had identified only two studies that they deemed to be of sufficient rigor in regard to quality measurement.

Burns (1996) discusses the multiple determinants of outcomes for emotional and behavioral disorders in children and adolescents. She suggests that a number of factors must work synergistically to achieve positive outcomes, including principles, incentives, adequacy of the service system, quality of treatment, child and family characteristics, the research base, and stakeholder preferences. In regard to principles, she cites five CASSP principles: services should be individualized, family-centered, community-based, provided in the least restrictive setting, and culturally competent.

Within the context of managed care, steps are being taken to shift financial incentives away from institutions and toward community-based care, thereby providing more and more incentives for providers to dispense care in the community. As for the adequacy of the service system, key questions regarding the “processes of care” include: Is the full continuum in place? Are the resources in the continuum sufficient to meet the needs of the covered population? Are behavioral health services coordinated with those provided in other human service sectors, such as health, education, child welfare, and juvenile justice? Are families involved in the planning and delivery of services? Are services provided in a timely and flexible manner?

According to Burns (1996), a quality-of-care literature for child mental health interventions is essentially non-existent, and a link between outcomes in mental health settings where care is usually given and those found in highly controlled efficacy studies of psychotherapy for children is weak (Weisz, Weiss, & Donenberg 1992). In terms of “intervening variables” or “covariates,” many child and family characteristics come into play, such as risk factors, illness severity, chronicity of illness, comorbidity, family strengths, availability of social support systems, case management skills, and adherence to professional recommendations.

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In a recent review, Burns et al. (1998) examined studies on the effectiveness of a range of interventions. In response to the question, “What outcomes do various service

components produce?" Burns provides the following summary: For inpatient/residential, there is very limited evidence. Shorter stay is associated with better outcomes. For psychotherapy, there is stronger evidence for highly controlled studies than clinic-based ones. Day treatment is effective for limited population; family involvement is essential to success. For psychotropic medication, there is minimal research on children or adolescents. In terms of family preservation, 70–96 % remain with family, effects short-term only. For crisis and emergency, placement prevention in 60-90 % of cases. For case management, initial studies point to positive outcomes for "high risk" groups. Wraparound services seem to lead to improved child/family functioning, with less restrictive placements beginning to emerge. Family support/education leads to improved family satisfaction, reduced stress, increase in parenting skills. In terms of therapeutic foster care, 62–89% were discharged to a less restrictive setting.

# Managed Care and Children's Mental Health

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"Managed care" implies that one or more of the following elements is implemented:

- limited choice of providers
- selective contracting
- financial incentives for providers
- gatekeeping
- physician profiling
- utilization review
- organizational culture

Managed care in theory is about creating "incentives to re-engineer clinical processes, including integrating patient care across services, locations and time." (Miller & Luft 1999) Managed care goals include cost control through improved efficiency and coordination, reduction in unnecessary or inappropriate utilization, increased access to preventive care and maintenance of the quality of care (Miller & Luft 1994). Miller and Luft's reviews of managed care performance (1994 and 1999) demonstrate equivocal results regarding the impact of managed care on quality of care. Even though there are plenty of anecdotes suggesting that the quality of care is worse under managed care, the evidence does not support this contention. In fact, some populations do better in managed care arrangements, particularly those that promote continuity and use of a medical home. Some groups admittedly do worse. Those include elderly with some chronic conditions in Medicare HMOs and other vulnerable populations, including those who are poor, on Medicaid, and have a chronic disease or special needs.

## Impact on Health Care Access and Quality

The above applies to general medical health care plans and primarily to adults. For children, the data are far from conclusive and depend on the type of provider reimbursement (capitation or fee-for-service), level of cost sharing (co-payments, premium subsidies), and the breadth of the benefit package (Szilagyi 1998). The impact of managed mental health care on children is even less understood, except that cost reduction strategies often lead to contracted benefits (mental health services are often the first to go) and/or a restricted benefit choice (Bergman and Homer 1998). Managed care has reduced costs by replacing inpatient care with ambulatory services, reducing the number of visits covered, and substituting social workers for psychiatrists and psychologists (Durham 1998). The impact of these maneuvers on access, outcomes, and quality of care are unknown, especially for children.

Studies of the impact of managed care on access and quality for children with mental health problems will continue to be severely hampered by the following factors: the rapid evolution of managed care, the turn-over of managed care organizations (failures,

mergers, acquisitions), and the lack of a consistent database that would allow tracking of outcomes.

## Trends

The most significant health care trend for this decade is the increased enrollment into managed care plans in both the private and public sector. The health care system began a new period of change in 1992–93, characterized by more demanding employer purchasers, more competitive health plans, intensified provider competition for health plan contracts, substantial cost-cutting efforts, lower rates for premiums, clinical practice changes, and pressure to re-engineer and integrate clinical processes, for example, disease management. In 1998, health care premiums began to rise again after several years of control. Thus, some markets may have experienced that area in the cost-quality curve where cost-cutting begins to affect quality of care, necessitating system adjustments and increased costs.

Another significant trend beginning in the mid-1980s was the emergence of behavioral health, an outgrowth of private sector managed care, that attempted to integrate mental health and substance abuse services. Under managed care, provision of mental health services has increasingly moved into “carve-out” programs to effect cost reductions.

Carve-outs are a rapidly expanding form of managing mental health care (Frank, McGuire & Newhouse 1995). Carve-out programs place behavioral health services under specialists who are contracted to provide mental health services, usually as an independent company and under a capitated arrangement. The advantages of carve-outs are that providers can focus only on specific conditions and offer competitive capitated rates. Mental health services are protected in terms of resource allocation and do not have to compete with medical and surgical services. Children with specific mental health problems are directed to the same provider group, therefore eliminating selection bias.

The disadvantages of carve-outs are that they are obviously not integrated with primary care. Behavioral health carve-outs often exacerbate the psyche-soma dichotomization and create incentives for the shifting of responsibility and cost. Physical and mental health care is provided separately. Communication between carve-out specialty mental health providers and primary care providers may be limited. The lack of communication may result in fragmented care, patient confusion, and potential problems, such as drug interactions. There are examples of ways in which communication can be facilitated in such carve-out arrangements. Patients can be asked to sign a waiver at the time of enrollment into behavioral health services thereby “allowing their PCP to receive information directly from their mental health provider.” However, at United Behavioral Health about half their patients approached to give releases to communicate information about their mental health treatment to primary care providers refuse to do so. Therefore, establishing communication between a carve-out and the primary care service may be difficult.

Emerging studies on mental health carve-outs describe changes in utilization and costs, primarily for adults. Adult studies show that mental health carve-outs can be cost-effective (Frank et al. 1996). Mental health carve-outs can achieve cost reduction in mental health service delivery by decreasing the number of outpatient sessions per user, decreasing inpatient admissions, decreasing length of stay, and decreasing the costs per day. Using six years of claims data, Goldman et al. report up to 40% reduction in mental health services cost through a mental health carve-out with U.S. Behavioral Health (Goldman, McCulloch, and Sturm 1998). This cost reduction was achieved without reduction in access to care, but, notably, quality of care measures were not available. Another study documented lower outpatient and inpatient costs leading the authors to surmise that a 30 to 40% cost reduction is a "minimum estimate of the impact of managed care carve-out." (McGuire 1998) A UCLA/Rand study of 1995–96 cost data from 24 carve-out plans showed that costs are lower in these plans than in traditional indemnity insurance plans, even though access is higher. The lower costs are a result of decreased hospitalization, a shift from inpatient to outpatient care, reduced payments per service, and intensive care management techniques (Sturm 1997). Carve-outs are likely to increase access to specialty care because patients do not need to contact their PCP, who might act as a gatekeeper. A concern about specialty care provided by carve-outs is that master-degree level therapists have largely replaced psychiatrists in order to decrease costs. However, 23% of costs in this study of carve-outs were due to psychiatrists compared to 10% in a 1986 Medical Outcomes Study of depressed patients in HMOs. A ten-year trend of declining benefits for behavioral health care has been tracked by the Hay Group of Arlington, VA. They found that between 1988 and 1997, medical and behavioral health benefits declined by 7% and 54% respectively.

Carve-in programs integrate behavioral health into a standard medical health plan, facilitating linkage between physical health care and mental health and substance abuse treatment. Mental health services are provided in group models which allow better coordination between primary care providers and mental health workers. Historically, the problem with carve-in approaches has been that mental health tends to be overlooked when multiple stakeholders within an HMO make priority decisions about monetary expenditures. Medical and surgical priorities tend to be prioritized over mental health. Carve-outs, on the other hand, tend to protect the mental health benefits.

### **The Cost of Displaced Utilization**

Lack of recognition of children's mental health problems may lead to high health care utilization and hide the costs of mental health in primary care. Children with mental health problems have been found to be high utilizers of health services in general (Jacobsen et al. 1980; Costello et al. 1988a). Pediatricians were more likely to identify emotional or behavioral problems in those children who received high levels of service (Costello et al. 1998b). This relationship has been documented beginning in preschool children and extending into adolescence. In a study of preschooler health care utilization in a private non-managed care system in Chicago, Lavigne et al. (1998) found that DSM III-R diagnoses among preschoolers have been associated with in-

creased emergency department use. Dimensional ratings of psychopathology among preschoolers appear to be more sensitive indicators and have been associated with both increased primary care utilization and ED visits. Higher CBCL scores are associated with greater utilization, suggesting a “dose response” relationship. Behavior problems may be better predictors of health care utilization than taxonomic diagnoses.

Kaiser-Permanente’s multi-center study on psychosocial disability included 1,800 children in six pediatric settings (Bernal et al. *in press*). This study included children ages 2–18 years (41% were 2–5 years of age), several ethnic groups (23% Latino, 14% black, 16% Asian, and 54% white), and both genders (51% male). Measures of psychosocial disability included Pediatric Symptom Checklist (PSC), Beck Depression Inventory (BDI) as well as parental and pediatrician reporting. The PSC was used to classify positive cases as internalizers cf. externalizers for purposes of cost comparison. Outcome measures included utilization (# of outpatient visits) and costs.

Results from multiple regression models predicted that the average log visits for internalizers was 7.6 compared to 4.3 visits for the total sample, 5.3 visits for externalizers, and 10.5 for children with chronic illness. The average log health care costs for the internalizers (\$805) and for externalizers (\$570) were higher than that of the total sample (\$393) but still less than that of children with chronic illness (\$1,138).

Among internalizers, regression models of cost and age predicted high levels of medical costs and very low levels of mean psychiatric cost at young ages. With increasing age from ages 2 to 17 years, the predicted medical costs of internalizers decrease from \$800 to \$400 (approaching medical costs of the whole sample) by age 17 years, while psychiatric costs of internalizers increase from 0 to slightly more than \$200. These patterns of utilization and cost represent the cost effect of non-recognition and delayed intervention. The same pattern is found for externalizers; however, they begin with lower predicted medical costs (<\$600) at age 2 years and end with higher psychiatric costs (nearly \$500). The rate and magnitude of increase in the psychiatric cost of externalizers with age is much greater than that for internalizers. This may be attributed to the possibility that parents, teachers, and pediatric primary care providers may identify externalizers more readily than internalizers.

The early increased costs among the internalizers implies that there is a delay in the detection of mental illness and institution of psychiatric services for internalizers. This supports the notion that pediatric psychosocial morbidity is undetected early in life, and results in displaced utilization in terms of medical visits. Internalizers thus overburden the pediatric primary care clinics before they are recognized and referred to psychiatry.

Many previous studies have shown that depression affects adult primary care utilization (Henk 1996). The utilization and costs of care for the parents of children studied above was also measured for one year prior to the child’s screening. For all parents in the sample the predicted visit average was 4.6 based on the sample multiple regression models. Depressed parents were predicted to have 0.2 visits more per point in their BDI score. The BDI status of the depressed parent added \$24 dollars more for *each* point above the BDI cutoff in their primary care utilization in the prior year. The models also predicted an additional 1.6 primary care visits per year for the parent of a chronically ill child. Thus, psychosocial disability among children not only in-



creases child utilization rates and the cost of care, but also is associated with an increase in parental utilization and health care costs.

“The costs of the status quo are considerable—in the unmet needs of children and families in the realm of mental health and development, in the increased utilization that we know occurs in the presence of children’s and families’ distress, and in the frustration and dissatisfaction of physicians. The cost on the other hand of a collaborative care arrangement is mostly unknown and needs to be studied, but possibilities exist for some costs to be covered by decreased utilization, at least in a capitated system, by reorganizing the office overhead expenses, and as a result of the increased efficiency and productivity of a logical and coordinated system of care.”  
*Ellen Perrin, MD*

## Cost Considerations

There are several problems documenting the cost effectiveness of children’s mental health programs in primary care. Returns on investments in child mental health are in the form of long-term outcomes, impact on other systems of care (juvenile justice, schools, etc.), and effects on other populations. Cost effectiveness studies need to include indicators and outcomes for both parents and children, not just one or the other. Interventions need to be designed, developed, implemented, and evaluated in an integrated care system. Evaluation needs to involve system-wide indicators and outcomes. Long-term studies are needed that examine the effectiveness of early mental health intervention in preventing or reducing adult mental health problems and disability.

Cost shifting describes what happens when a change in health care service or a technological innovation occurs and results in the shifting of cost away from the payer who pays the cost of current usual care. For example, an innovation that saves hospital days may increase the financial and time burden on family caretakers. Cost shifting may not be immediately measured in short-term outcomes of medical systems but as savings in other systems, i.e., school, probation, parental health and utilization, or parental work productivity.

Cost offset usually refers to the reduction in medical care utilization that is attributable to mental health treatment of individuals with psychosocial problems, or the potential medical cost savings from improved psychologic or psychiatric care (Simon & Katzelnick 1997). In order to reduce medical costs, utilization managers have been advised to increase accessibility to mental health services for those patients who are high utilizers of general medical care (Olfson, Sing & Schlesinger 1999). Among children ages 5 to 11 years, mental health treatment of psychosocial problems was associated with decreased use of specialty care, but no change in use of primary care (Kelleher and Starfield 1990). Among adults, Gabbard et al. (1997), in a review of the economic impact of psychotherapy with adults, found that 8 of the 10 clinical trials with random assignment and all eight of the studies without random assignment suggested that psychotherapy reduces total costs. Much of the cost curtailment results from reductions in inpatient treatment and decreases in work impairment.

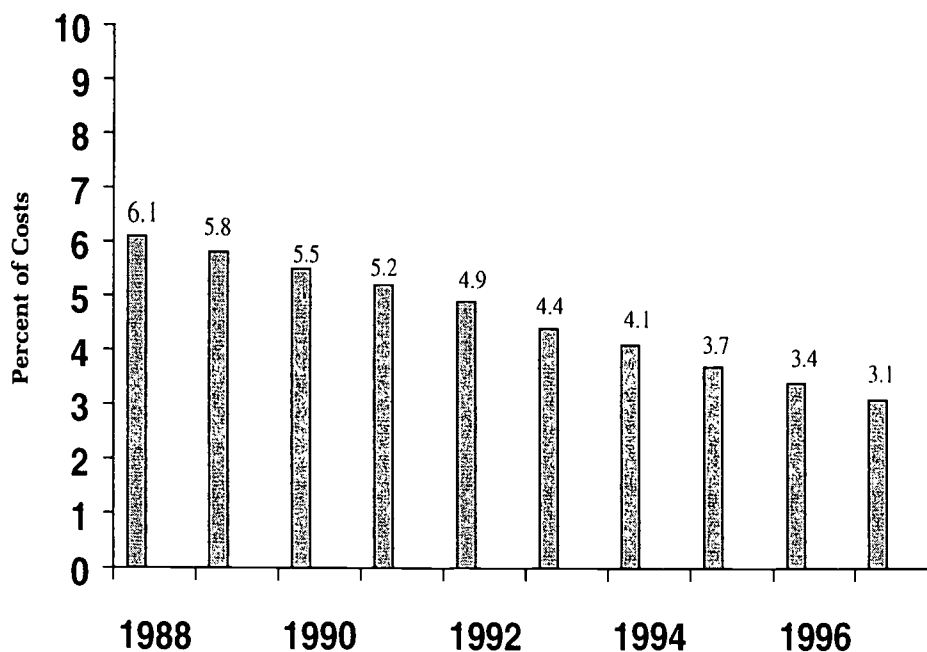
Longitudinal studies at this point are limited to descriptions of the evolution of childhood psychiatric disorders in adulthood and do not examine the impact of treatment on this process. A longitudinal study of adolescents followed into young adulthood has shown a significant relationship between earlier adolescent drug use and later depressive disorders in young adulthood while controlling for significant covariates (Brook, Cohen & Brook 1998). The amount and frequency of drug use in this study was directly associated with the risk of depressive and conduct disorders in adulthood. However, it remains unclear whether substance abuse is causally related or merely a marker of some other process that leads to adult psychopathology. This study did not include a study of the effects of early substance abuse treatment on subsequent mental health status.

Cost sharing is a managed care strategy designed to decrease inappropriate utilization. What is the impact of cost-sharing plans on mental health? In the five-year Rand Health Insurance study, subjects were randomized to various cost sharing health insurance plans, which included a free plan in the study design. Results pertaining to mental health show greater utilization of mental health services by those in the free plan. However, at the end of the evaluation, a trend towards better mental health was noted for individuals in the cost sharing plans compared to those in the free plan (Brook 1997), suggesting that free plans do not lead to better mental health. Specific impact of cost sharing on children's mental health care utilization is not known.

What is the cost of adding unlimited mental health services to a physical health plan? The UCLA/Rand study of 1995-96 cost data from 24 carve-out plans that offer unlimited mental health and substance abuse coverage showed that removing the usual \$25,000 limit on mental health benefits would raise group health insurance costs under managed care by only one dollar per enrollee per year. However, the largest cost increase would be for children, because "children with mental health problems are very expensive users. Therefore, parity regarding limits for mental health or substance abuse care will primarily benefit families with seriously mentally ill children." (Sturm 1997)

Behavioral health care costs as a percent of total health care costs have decreased as shown in Figure 2.

**Figure 2. Behavioral Health Care Cost as a Percent of Total Health Care Costs**



The Health Care Financing Administration examined spending for mental and substance abuse as a percentage of the overall health care spending and found that it had declined from 9% in 1986 to 8.1% in 1996 (Kaplan 1999). Several billions of dollars are allocated each year for behavioral health services, a large percentage of which is spent on the most severely mentally ill. Coverage of costs associated with such services is based on the premise that treatment outcomes can be defined and measured. Accountability systems are being developed to defend the allocation of costs.

### **Best Practice Guidelines: An Example from Kaiser-Permanente**

Child, adolescent, and family mental health care, in many ways, is more amenable to programmatic planning than categorical services used under the fee-for-service system. When operating in the absence of data, Kaiser Permanente, Northern California, gathers providers, patients, purchasers and others together to describe what program meets their needs. The result of this process is 'best practice guidelines'. Essential elements of their program include the following: careful initial assessment and timely referral, collaborative treatment, an array of urgent care services, and internal research.

Initial telephone assessment is done by trained mental health clinicians who focus on sending the child and family to the most appropriate service as soon as possible. A comprehensive face-to-face evaluation of the presenting problem is then done. This is the point where under-diagnosis may undermine the referral process. The operative word here is comprehensive, because at this point, the provider's ability to recognize the severity of the presenting problem determines to a certain extent the adequacy of the treatment offered. Timely referral to appropriate treatment is the next essential element. The overall treatment approach includes the family. It is rare for the family not to be involved. Occasionally, this happens for teenagers after the initial evaluation, when, for example, an agreement to that effect is made with the child or family. Interdisciplinary collaboration is one of the advantages of a group model HMO, in which it is quite easy to interact with adult psychiatry, chemical dependency, pediatrics, obstetrics-gynecology, health education, and/or social services.

The scope of treatment services offered include screening and triage, crisis intervention/intensive outpatient program, evaluation for diagnosis and treatment planning, and multi-modal treatment alternatives. These include individual and play therapy, family therapy, group therapy, psychopharmacological monitoring and maintenance, parent training and behavioral health education, pediatric liaison service, case management, partial hospitalization and inpatient services. The TOTS program is a toddler/preschool program for families with children who have behavioral, temperamental or social/emotional difficulties. This is a ten-session, 1.5 hour/week intervention administered by psychologists that utilizes parent support groups, videotaped parent-child sessions, therapeutic child play groups, and in-session coaching for enhancing parenting skills. The integrated urgent services branch was designed to improve the previous system of care comprised of outpatient and inpatient psychiatry in which a number of adolescent hospitalizations were occurring that were high cost and unacceptable to the adolescents. Adolescents were reluctant to be stigmatized by

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a psychiatric hospitalization. This was supported by the psychiatrists, respectful of their patients' vulnerable self image. The new system incorporated the already existing outpatient services, with inpatient services when necessary, using safety for the criterion for hospital admission. A number of other service options were created and include partial hospitalization, 23-hour observation, intensive outpatient program, case management, and a dedicated IUS (Intensive Urgent Services) "champion." The partial hospitalization or 23-hour observation options are used for children who are out of control at the moment and need a safe setting that may or may not be hospital connected. After re-evaluation, these children can, one hopes, be moved into intensive outpatient programs.

The intensive outpatient program meets three times per week and involves individual work with the child as well as family therapy. At each facility there is a dedicated IUS champion who manages the program and assists others in utilizing the programs most efficiently. This person is always available for consultation and can advise on available treatment options and the next best step given the clinical situation. The effect of this system of care has been increased coordination of care among all practitioners, improved parental satisfaction, fewer complaints, and a 50% decrease in child inpatient days. Other outcomes have not been measured due to the limited number of children available for study and the prohibitive cost of studying those few children more intensively.

Kaiser-Permanente ADHD guidelines have been developed jointly by pediatrics, child psychiatry, and behavioral health education. Uniform screening is done initially in either pediatrics or mental health by phone. CBCL scoring and other instruments are sent to the parent's home and another set sent to the school for teacher evaluation. The child is then evaluated by a pediatric nurse who specializes in ADHD, followed by a meeting with a physician in pediatrics. The parents, pediatrician, and nurse decide on the next steps for diagnosis or treatment. For most children, this includes a behavioral health education program for ADHD that is primarily geared towards the parents. Medication is offered by either pediatrics or psychiatry and based on the clinician's assessment of the severity of the problem. For higher levels of co-morbidity, children are more likely to be treated by a mental health specialist. Socialization groups for children with ADHD are offered, as well as individual or family treatment in mental health services, all dependent on the situation and expressed preferences. Parents of children with ADHD want different things; some prefer a lot of involvement with CHADD, others want reading materials. Some prefer to check the Kaiser-Permanente website and review the educational materials on-line. An important goal for the various professionals involved with these families is to try and interest parents in all of the different modalities available. This guiding principle is based on the belief that the more involved parents become, the more likely it is that they will direct the professional staff toward the most acceptable and appropriate treatment for their child or adolescent.

36 Interaction with outside agencies is not easier for an HMO than other health service models. Capitation for large groups works to the advantage of child, adolescent, and family mental health services because it allows for system level interventions, as opposed to individual fee-for-service level interventions. Although a programmatic approach works within the MCO structure, capitation poses a very large challenge to

integration of mental health services across systems of care, i.e., social services, schools, and health care.

Several internal research branches through the Kaiser-Permanente system have been key to guiding internal efforts at improvement, e.g., describing the economic burden of undetected psychosocial morbidity in the pediatric population, studying the impact of undiagnosed parental depression on families served in pediatric primary care, outcomes of adults and children in primary care who are diagnosed with depression and are monitored by extensive nurse telephone follow-up, outcomes of children placed on psychotropic medications compared to usual care, and outcomes of a psychosocial intervention among parents, spouses, and children in a family depression education project.

“Now we have a tower of Babel where everybody is asking for different quality standards, certainly in the adult mental health field. In the child mental health we have an advantage since there is so little out there.”

*Mary Jane England,  
MD*

### **Quality, Managed Care, and Children’s Mental Health**

The Institute of Medicine 1990 and 1997 defines quality of health care as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes, and are consistent with current professional knowledge.” One can posit the following relationships between quality and health service use, categorized as service overuse, misuse, or underuse. Fee-for-service environments traditionally were characterized by service overuse. In managed care, service overuse can be reduced, thereby decreasing costs. Service misuse, such as poly-pharmacy, can also be addressed in managed care settings by cost-reduction strategies. Capitated environments are most at risk for service underuse. In addressing service underuse, managed care systems will need to increase accessibility, availability, screening, and diagnosis, thereby increasing costs. This creates a dilemma for primary and secondary prevention efforts unless there is some way to factor in a comparison of short-term and long-term costs. This requires long-term financial planning on the part of managed care organizations. Given the high rate of turn-over of enrollees and MCOs themselves, the current environment is not conducive to long-term assessments.

Quality assurance (QA), a healthcare legacy, is the “bad apple” approach to quality in managed care settings. Practices are audited to ensure they do not dip below a certain threshold of care that is considered tolerable quality. Quality improvement (QI), the “dashboard approach,” uses continuous quality monitors which depend heavily on measurable indicators. The legacy for QI is in manufacturing, where administrative and process measures are used to monitor productivity and efficiency. At present, it is still unclear what impact QI has had on the health care quality.

Current QI measures include access, utilization, process (timeliness, efficiency of care delivery), clinical outcomes, and patient satisfaction. Process measures include how quickly you can get an appointment with a provider, how quickly a patient can get care depending on the urgency or the need, and how efficiently that care is delivered. Whether or not health care will compete on quality will depend on the development of better quality indicators. The report card approach uses measurable indicators of best practices and compliance measures. What is needed are succinct quantifiable measures of efficacy, distillations of what best practices are, and measures of provider adherence to best practices. Patient level determinants must also be addressed. For

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example, oversight and monitoring mechanisms are needed in clinical practices in order to improve patient adherence to treatment.

Current quality measures (HEDIS, NCQA, JCHAO) and accreditation measures often do not reflect the needs of our youngsters. Quality indicators have to incorporate the developmental needs of children and their dependency on the adults in the community. Measuring health status and addressing cultural competency must also be considered in developing these measures.

Functional outcome measures are needed to measure the quality of child mental health services. The American College of Mental Health Administration convened a group of practitioners and family members to begin to develop uniform measures. Examples of measures for children could include: 1) children should live in the homes of their families or surrogate families; 2) they should be in school; 3) their grades ought to improve; 4) they should get good physical mental health care; 5) they should be safe from victimization, abuse, and neglect, and not in trouble with the law; and 6) they should have social supports and developmentally appropriate activities. All of these can be measured. The use of functional outcome measures is the most effective way to demonstrate that these programs are actually working and merit future funding.

Provider incentives may be needed to engage providers in the process of quality improvement. Creative performance-based payment systems are needed that guard against potential overuse in the fee-for-service environment and potential under-use in the capitated environment. MCOs have been experimenting with combinations of small base fees for capitation and then rewarding providers with fee-for-service on top of that capitated base contingent on quality-based performance measures. The impact of financial incentives on primary care physician practices is still debated. In one study of 766 primary care physicians in California, physicians reported that their performance is influenced by incentives in that they felt pressured to limit referrals or to see more patients depending on the incentive design (Grumbach et al. 1998). However, more objective measurements of utilization and cost in another study of primary care physicians in Washington State failed to demonstrate any impact on these outcomes (Conrad et al. 1998). Neither of these studies examined mental health services or children specifically. Therefore, evaluations of the impact of performance-based payment systems for children's mental health service delivery is needed.

Whether the health care industry will ever compete on quality will also be determined by outcomes that can be achieved and attributed to QI. Employers are interested in whether or not their employees are functioning well in the workplace. Clinicians tend to focus more on symptom reduction than function. The problem measuring function is that the questionnaires are long and therefore not practical to administer. If shortened, these questionnaires are quicker and easier to use, but often shorter versions lose their ability to measure change over time. Thus, shorter instruments may fool providers into thinking they have good outcomes, when in effect, long-term costs are accruing. These costs may be greater because the long-term outcome is poor.

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Children with special health care needs are expected/believed to fare least well in managed care environments that restrict benefits and access to pediatric sub-specialists or interrupt continuity of care. Managed care could be and has been used as an "educational tool" for providers and patients in order to improve health service ac-

cess, quality, and outcomes (Silver 1997). The use of practice guidelines, restricted formularies, and disease management programs are strategies that have been proposed as means of reducing practice variation and inappropriate care. How effective these strategies have been for children with mental health problems is unknown.

A recent Institute of Medicine report provides several recommendations on improving quality in behavioral health (Inst of Med 1997). The components of the quality of care listed in that report include the following:

- There should be a reasonable range of options from which to choose in a managed care plan. This could apply to the scope of the benefits package, the number and type of providers included in the plan, or the variety of treatment options covered by the plan.
- Confidentiality and privacy have to be balanced with a need to share information among health care provider in order to coordinate care.
- There ought to be a “demonstrated respect” for the cultural context of the individual or population.
- Lastly, an emphasis on functional assessments or outcomes as a measure of treatment success should be evident.

The Alliance for the Mentally Ill developed a report card with nine criteria for excellent treatment of adults with serious and persistent mental illness and graded managed care organizations on these criteria. However, neither of these reports is specific to children, thus concerns specific to the mental health needs of children have not been assess in this fashion (Jellinek 1994).

## **Research Partnerships with Managed Care**

One challenge in research in the carve-out industry is the mergers and acquisitions that have characterized the for-profit companies. As a result of such mergers and acquisitions, system platforms change, the database structure and elements change, and even the employees that have relationships with researchers leave. A high rate of personnel turnover within MCOs undermines attempts at standardization, research training, and outcomes tracking. Thus research agreements may not come to fruition due to MCO acquisition, merger, or failure.

Another challenge is that one has to dis-aggregate the design of the benefits package from the management of care within the health service delivery system. Processes of care management can range from a simple review of impatient services utilization to more complex care management. Examples of this include mental health case management in which care managers call patients to see if they made their appointment, or call providers to see if they have adhered to a particular treatment plan. It can also include arranging for care managers to manage complex cases more intensively and to coordinate their care among multiple providers. For-profit MCOs have proprietary interests they wish to protect. They limit access to their databases and do not feel compelled to publish their performance in the public domain (Durham, 1998). Database challenges also include lack of standardization among measures and indicators

used by various providers. This is due in part to the naturalistic environment of health service delivery among MCOs as well as the heterogeneity of training various types of mental health providers receive. Another database problem is membership fluidity. The proportions of short-term cf. long-term members can be quite variable among plans, and selection biases may be operative. Coding and mapping of these databases can be difficult and not amenable to research objectives. Medical records could be handwritten text, computerized text, or codified depending on the degree of electronic sophistication available. Databases may be set up for primarily financial or billing purposes, like claims databases, and therefore not contain satisfactory clinical information, and that information may not be linked to or aligned with other desirable data in such a way that it can be easily queried.

Setting the above limitations aside, managed care settings may be ideal for the following types of research. The cost effectiveness of mental health compared to primary care screening and clinical management of children with mental health problems could be studied in non-integrated systems. The effectiveness of various types of mental health interventions could be studied in those managed care settings dealing with large numbers of children. Drug trials could be and are conducted in managed care settings. Long-term outcomes could be examined in stable managed care environments that are shielded from MCO turnover. Disease management approaches are best evaluated in these naturalistic environments that more realistically approximate the effectiveness of these approaches.

## Managed Care Contracting

What is medically necessary is a question that commonly arises in defining the scope of benefits or providing mental health services for children. Brook (1997) writes that necessary "should be broadly defined to include care for which the benefits exceed the risks, physicians should feel that they could be sued if the patient is not offered that care, health professionals should be deeply concerned if they are unable to offer that care to their patients." Debates on medical necessity are ethical, policy, or political debates. "What is necessary is what we agree is a necessary means to achieve our desired outcomes." Using the example of deciding whether a visit to a school is medically necessary, the question really boils down to whether or not this visit is conducive to better outcomes. However, it is more often reduced to what social system will pay for that service. Is it health care, education, or parental responsibility? Thus, the issue of social division of labor arises. Another example of this is who pays for psychological testing? If it is necessary for a neuropsychiatric diagnosis, then health care pays for it. If it is educational need, then the schools pay for it. For those many grey areas, the family is often left with this responsibility. Another common example is that psychological treatment of ADHD or conduct disorder is not covered by certain managed care plans.

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What is the minimum set of mental health benefits that should be included in a managed care contract with a primary care provider? The Bazelon Center for Mental Health Law in Washington D.C., has recommended contract language for defining medical necessity. The Bazelon Center has also worked on the impact that mental health par-



ity laws are expected to have on children's mental health services (Frank, Koyanagi & McGuire 1997). Specific safeguards have to be worked out on a case-by-case basis, including ensuring that substitutions with generic psychotropics are in the best interest of the patient and that truncation of services to vulnerable, seriously mentally ill patients does not occur.

# A System of Care

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“What is needed here is a system change that is actually pretty simple...it's the opposite of the current trend toward mental health carve-out—it's carving in.”  
Ellen Perrin, MD

Currently this nation has a non-system for child and family mental health. The traditional health benefit is artificially limited. Parity is still missing across this country. Mental health services have always been carved out in many ways. They have been largely relegated to a public system because mental health was not accepted within the traditional medical enterprise. Then, Community Mental Health Legislation again carved out mental health services. Now there are an estimated 160 million Americans who are in some kind of carved out managed care. Even though the individuals and families may be participating members of an HMO, their mental health services may not be integrated in any meaningful way with the rest of their health and welfare. Although several integrated managed care organizations are notable exceptions, there is a hiatus in care and a non-system for children, adolescents, and their families, in which treatment occurs in disparate and non-interactive systems.

As a result of the increasingly recognized inadequacy of mental health service system for children and youth, the system of care model was proposed by Stroul and Friedman (1986) and refined by Kutash and Rivera (1996). This model encompasses coordination of multiple services to meet the needs of children and adolescents with mental health problems while remaining at home and in their communities and preserving the family unit. The components within a system of care include the following services: mental health, social services, education, health care, substance abuse prevention and treatment, vocational and recreational opportunities and “operational services” (support services, such as case management, support groups, legal aid that enable the entire system to operate).

## The Systems Approach

The goals for systems of care are shown in Figure 3.

**Figure 3. Goals for Systems of Care**

☛	To consolidate categorical programs and integrate efforts
☛	To develop strong clinical processes based on individualized, strengths-baseds, family-friendly care
☛	To establish family leadership and support and involvement with every aspect of program development
☛	To develop broad and flexible service capacity
☛	To develop sophisticated administrative systems
☛	To establish accountability processes for good outcomes for children and their families
☛	To insure that service delivery is directly responsible to community organizations at the neighborhood level

The first goal is to consolidate categorical programs and integrate efforts. In an effort to preserve mental health services, many individuals and institutions have accentuated this problem by responding to narrowly targeted initiatives and building service delivery systems in subspecialty areas—children with serious mental illness, adolescents who have sexually aggressive behaviors, substance abuse programs, school violence prevention, etc. Regardless of whether based in pediatrics, family practice, or child psychiatry, there is a dearth of generic community and strength-based, family-friendly programs with significant family leadership in its governance.

Many recognize the need for integrated child health networks and full continuum of care without artificial barriers or differentiation. (See below, Figure 4.) Although there is information available to guide the improvement of community health status, including clinical preventive strategies, there is no single leadership fiscally responsible for improving the health of the community in an area such as adolescent suicide. In capitated systems, there is no process to include risk adjustments for special populations, performance standards, or a system of accountability.

**Figure 4. Integrated Child Health Networks**

☛	Full continuum of care
☛	Improved community health status
☛	Capitation with risk adjustment for special populations
☛	Performance standards
☛	Accountability

“System of Care” studies (Bickman 1996; Bickman & Salzer 1997) are promising in that integrated systems provide better access to treatment and higher client satisfaction, but at higher cost and with questionable differences in terms of clinical and functional outcomes. Bickman (1996) reported on the findings of an \$80 million project (the Fort Bragg Evaluation) designed to test whether a continuum of mental health and substance abuse services for children and adolescents is more cost-effective than services delivered in a typical fragmented system. Findings suggest that an integrated continuum was implemented. The continuum resulted in improved access, greater continuity of care, more client satisfaction, and less restrictive interventions. Yet, the cost of care was higher, and clinical outcomes were no better than those at the comparison site. Bickman noted, “Therapeutic interventions can work. We have just not been able to establish their effectiveness in real-world conditions.”

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Documenting the outcomes and evaluating services for children and families is a complex and vexing challenge, particularly since the multiple agencies involved are likely to have different needs. Despite the pressure to reform and innovate a system of care, accountability often involves outcomes not addressed by single interventions or agents.

Cost remains yet another intrusion into the effort to design and monitor improved services for children and families. Hernandez, Hodges, and Cascardi (1998) offer a

“I would be remiss if I didn’t mention that schools are really good partners. They are where these kids are that pediatric providers see for 13 minutes. Collaboration between schools and pediatricians and mental health providers in general has been difficult because we have not had a lot of input from health care providers at schools. Professionals at schools have trained themselves to be diagnosticians, and school nurses and teachers are now beginning to do the labeling and refer parents directly. So who we collaborate with and the mechanisms we put in place are really crucial.”  
*Linda Taylor, PhD*

conceptual framework for an outcome-oriented child-serving system in which outcomes are measured and used in the context of other information and in which key stakeholders are involved and share leadership and support of the system of care. They note the need for a shared language and consensus regarding ‘outcomes’, the recognition that treatment is a process rather than a single event, and the identification of outcomes from several domains. Without consensus about each of these areas, outcomes research regarding a system of care is doomed to fail.

Other promising approaches include case management, therapeutic foster care, home-based treatments, crisis and emergency room interventions, family support, and the use of mentors. The need for a coordinated, family-centered system of care begs for evidence to support re-integration. The following questions need to be addressed:

- Does communication between primary and specialty care improve quality of care?
- Is continuity of care and quality of care better when services are “under one roof”?
- What is the ideal primary care behavioral relationship?

The issue of a system of care is larger than the concept of wrap around services. A system of care needs to be in place for all children, not only children with severe mental illness for whom the system of care is most frequently considered. An important mediating variable in children’s mental services is coverage. While universal coverage is needed, it will only be achievable with recognition and acceptance of the need for limits, as demonstrated in Canada. If mental health services for children are to be expanded, a counter-intuitive position must be adopted: recognizing, accepting, and advocating for limits. Priority settings need to be explicit. The Oregon Health Plan experience has demonstrated that when limits are recognized, explicit priorities set, and a level playing field established for all health care, mental health services are ranked highly on the priority list (Jacobs, Marmor & Oberlander 1999). Therefore, in order to improve child coverage, it is necessary to recognize and accept limits and encourage an explicit priority setting process in resource allocation.

## Schools

School based health centers provide a unique opportunity to provide access to mental health services and improve health care for children and adolescents, including children who are from immigrant families, have special needs, or who have not been previously enrolled into health insurance programs. The school environment allows for the optimal integration of home, community, school, and behavioral/mental health service services in the most naturalistic and child-centered way.

It is not a new insight that mental health and psychosocial problems must be addressed if schools are to function satisfactorily and if students are to learn and perform effectively (see Cowen et al. 1963; Flaherty, Weist & Warner 1996; Kirst & McLaughlin, 1990; Lambert, Bower & Caplan 1964; Powers, Hauser & Kilner 1989; Tyack, 1979, 1992; Zigler & Lang, 1991). Over the years, schools have instituted pro-

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grams designed with a range of mental health and psychosocial problems in mind (school adjustment and attendance problems, dropouts, physical and sexual abuse, substance abuse, relationship difficulties, emotional upset, delinquency and violence—including gang activity). School-based and school-linked programs have been developed for purposes of early intervention, treatment, crisis intervention, and prevention (including programs to foster positive social and emotional development).

However, with expansion of school-based mental health and psychosocial interventions have come growing concerns about their effectiveness and place in schools. Among some segments of the population, schools are not seen as an appropriate venue for mental health interventions. The reasons vary from concern that such activity will take time away from the educational mission to fear that such interventions are another attempt by society to infringe on family rights and values.

With proliferation of school-based and linked services, a variety of systemic concerns has arisen. The most basic problem is the dearth of data on results. In general, available evidence is insufficient to guide formulation of policy mandating specific approaches. At best, work accomplished to date provides a menu of promising prevention and corrective practices; the search for better approaches remains a necessity. Relatedly, there is the problem that planning and implementing programs and services often occurs in an unsystematic and ad hoc fashion. As widely discussed, the ensuing fragmented and piecemeal activities are an inefficient use of limited resources (Adelman & Taylor 1997; Adler & Gardner 1994; Center for the Future of Children 1992; U.S. Dept of Ed 1995; U.S. GAO 1993. And even more fundamental is the degree to which schools marginalize efforts to address barriers to student learning.

Concern about the current state of affairs naturally stems from awareness that noncomprehensive and piecemeal approaches limit efficacy and work against cost-efficiency. Limited efficacy seems inevitable as long as a reasonably full continuum of necessary programs are unavailable; limited cost effectiveness seems inevitable as long as related interventions are carried out in isolation from each other. From this perspective, many doubt that major intervention breakthroughs can occur without a comprehensive and integrated programmatic thrust (Adelman & Taylor 1994; Anthony, Cohen & Kennard 1990; Center for the Future of Children 1992; Hodgkinson, 1989; Kagan, Rivera & Parker 1990). To redress concern over piecemeal and fragmented approaches, greater understanding is needed with respect to the broad nature and scope of (a) the problems that must be addressed, (b) the programs needed to ameliorate the problems, and (c) the mechanisms necessary to ensure programs remain mobilized and function cohesively.

If schools are to work effectively on mental health and psychosocial concerns, two major avenues of conceptual and empirical endeavors must be pursued. First, steps must be taken to improve how problems are classified and to minimize the degree of misdiagnosis that currently is overwhelming school-based and linked services. At the same time, greater efforts must be made to develop comprehensive, multifaceted, and integrated intervention approaches.

Classifying problems requires a broad context. Some youngsters do have physical disabilities and mental disorders that can interfere with facets of development and learning. This, however, is not the case for the vast majority. And, even those who

“Probably as many as 85% of the kids diagnosed as having ADHD and LD are really garden variety learning and behavior problems. Because so many are misclassified, a great deal of research on treatment effectiveness has less to say about ADHD and LD than it does about learning and behavior problems in general.”

*Howard Adelman, PhD*

have such internal problems usually have assets/strengths/protective factors that can counter deficits and contribute to success. Most learning, behavior, and emotional problems seen in schools stem from situations where (a) external barriers are not addressed and (b) learner differences that require some degree of personalization by instructional systems are not accounted for. Furthermore, the problems often are exacerbated as youngsters internalize the frustrations of confronting barriers to development and learning and the debilitating effects of performing poorly at school.

The litany of barriers facing children and adolescents is all too familiar to anyone who lives or works in communities where families struggle with low income. In such neighborhoods, school and community resources often are insufficient to the task of providing the type of basic opportunities found in higher income communities. Furthermore, the resources are inadequate for dealing with such threats to well-being and learning as gangs, violence, and drugs. In many of these settings, inadequate attention to language and cultural considerations and to high rates of student mobility creates additional barriers not only to student learning but to efforts to involve families in youngsters' schooling.

Parents and teachers often say, "This kid is starting to have significant problems." The present system sends them away until the problem is severe enough to warrant services.

For example, children cannot qualify for screening by the IEP team for special education until their problems are severe. *Howard Adelman, PhD*

How many are affected? Estimates vary. With specific respect to mental health concerns, between 12% and 22% of all children are described as suffering from a diagnosable mental, emotional, or behavioral disorder—with relatively few receiving mental health services (Costello 1989; Hoagwood 1995). If one adds the many others experiencing significant psychosocial problems, the numbers grow dramatically. Harold Hodgkinson (1989), director of the Center for Demographic Policy, estimates that 40% of young people are in "very bad educational shape" and "at risk of failing to fulfill their physical and mental promise." Many live in inner cities or impoverished rural areas or are recently arrived immigrants. The problems they bring to the school setting often stem from restricted opportunities associated with poverty, difficult and diverse family circumstances, lack of English language skills, violent neighborhoods, and inadequate health care (Dryfoos 1990; Knitzer, Steinberg & Fleisch 1990). Societal inequities obviously affect the proportions of students at a school affected by external barriers. The reality for many large urban and poor rural schools is that over 50% of their students manifest learning, behavior, and/or emotional problems.

At the same time, it should be evident that, although the proportions differ with respect to a school's demographics, no school is exempt from learning, behavior, and emotional problems caused by classroom programs that are not well-designed to account for individual differences in student motivation and capability (Adelman & Taylor 1994). In addition, a significant range of out-of-classroom mental health and psychosocial concerns arise at every school, every day (Dryfoos 1998). Fortunately, relatively few youngsters have severe and pervasive problems. Too many, however, are manifesting moderate and multiple problems (e.g., behavior problems, underachievement, emotional upset, substance abuse).

From a classification perspective, it is essential to differentiate carefully between psychopathology and psychosocial problems. A useful starting point is provided by adopting the type of broad scheme proposed by Adelman and Taylor. (See Adelman 1995; Adelman & Taylor 1994.) Starting with a transactional view of the

determinants of behavior, they initially categorize problems along a continuum that separates those caused by internal factors, environmental variables, or a combination of both.

As outlined in Figure 5, problems caused by the environment are placed at one end of the continuum and referred to as Type I problems. At the other end are problems caused primarily by pathology within the person; these are designated as Type III problems. In the middle are problems stemming from a relatively equal contribution of environmental and person sources, labeled Type II problems. Thus, in this scheme, diagnostic labels meant to identify extremely dysfunctional problems caused by pathological conditions within a person are reserved for individuals who fit the Type III category.

**Figure 5. A Continuum of Problems Reflecting a Transactional View of the Locus of Primary Instigating Factors\***

<b>E</b> <b>Problems Caused</b> <b>by Factors in</b> <b>Environment</b>	<b>E ↔ P</b> <b>Problems Caused</b> <b>Equally by E and P</b>	<b>P</b> <b>Problems Caused by</b> <b>Factors in the Person</b>
E	E ↔ p	E ↔ P
E	e ↔ P	P
Type I	Type II	Type III
Caused primarily by environments and systems that are deficient and/or hostile	Caused primarily by a significant mismatch between individual differences and vulnerabilities and the nature of that person's environment (not by a person's pathology)	Caused primarily by person factors of a pathological nature
Problems are mild to moderately severe and narrowly to moderately pervasive	Problems are mild to moderately severe and pervasive	Problems are moderate to profoundly severe and moderate to broadly pervasive

\*In this conceptual scheme, the emphasis in each case is on problems that are beyond the early stage of onset. Adapted from Adelman & Taylor (1993).

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At the other end of the continuum are individuals with problems arising from factors outside the person (i.e., Type I problems). Many people grow up in impoverished and hostile environments. Such conditions should be considered first in hypothesizing what initially caused the individual's behavioral, emotional, and learning problems. By first ruling out environmental causes, hypotheses about internal pathology become more viable.

To provide a reference point in the middle of the continuum, a Type II category is used. This group consists of persons who do not function well in situations where

their individual differences and minor vulnerabilities are poorly accommodated or are responded to hostilely. The problems of an individual in this group are a relatively equal product of person characteristics and failure of the environment to accommodate that individual.

There are, of course, variations along the continuum that do not precisely fit a category. That is, at each point between the extreme ends, environment-person transactions are the cause, but the degree to which each contributes to the problem varies. Toward the environment end of the continuum, environmental factors play a bigger role (represented as  $E \leftrightarrow p$ ). Toward the other end, person variables account for more of the problem (thus  $e \leftrightarrow P$ ).

Clearly, a simple continuum cannot do justice to the complexities associated with labeling and differentiating psychopathology and psychosocial problems. Furthermore, some problems are not easily assessed or do not fall readily into a group due to data limitations and comorbidity. However, the above conceptual scheme shows the value of starting with a broad model of cause. In particular, it helps counter the tendency to jump prematurely to the conclusion that a problem is caused by deficiencies or pathology within the individual and thus can help combat the trend toward blaming the victim (Ryan 1971). It also helps highlight the notion that improving the way the environment accommodates individual differences may be a sufficient intervention strategy. The implications of all this for policy and practice, of course, are immense.

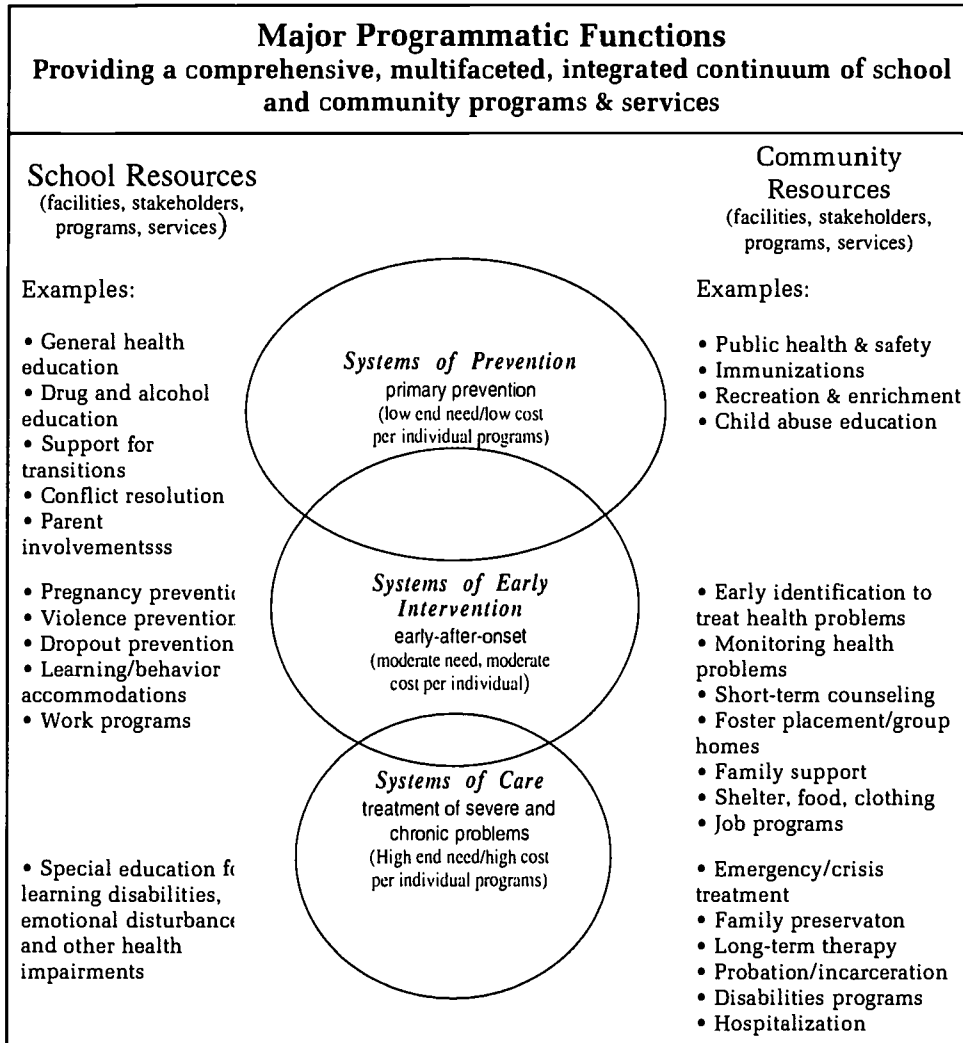
Amelioration of the full continuum of problems illustrated above (e.g., Types I, II, and III problems) generally requires a comprehensive and integrated programmatic approach (e.g., mental health, physical health, social services). That is, any one of the problems may require the efforts of several programs, concurrently and over time. This is even more likely to be the case when an individual has more than one problem. And, in any instance where more than one program is indicated, it is evident that interventions should be at least coordinated and, if feasible, integrated.

For the most part, however, interventions are developed and function in relative isolation of each other. One result is that an individual identified as having several problems may be involved in programs with several professionals working independently of each other (sometimes within the same agency). Similarly, a youngster identified and treated in special infant and pre-school programs who still requires special support may cease to receive appropriate help upon entering school.

To illustrate the type of comprehensive model that emerges from a focus on both psychopathology and psychosocial problems, a continuum of interventions for addressing behavioral, learning, and emotional problems is outlined in Figures 6 and 7. The continuum ranges from programs for primary prevention (including the promotion of mental health) and early-age intervention—through those for addressing problems soon after onset—on to treatments for severe and chronic problems. With respect to comprehensive and multifaceted approaches, the continuum highlights that many problems must be addressed developmentally and with a range of programs—some focused on individuals, some on environmental systems, some on mental health, and some on physical health, education, and social services. With respect to concerns about integrating programs (e.g., to avoid piecemeal approaches), the model under-



Figure 6. Systemic Collaboration



Adapted from Adelman and Taylor (1993).

scores the need for concurrent interprogram linkages and for linkages over extended periods of time.

Systemic collaboration is essential to establish interprogram connections on a daily basis and over time to ensure seamless intervention within each system and among *systems of prevention, systems of early intervention, and systems of care*. Such collaboration involves horizontal and vertical restructuring of programs and services:

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- **Between jurisdictions:** school and community agencies, public and private sectors, among schools, or among community agencies
- **Within jurisdictions:** school districts or community agencies (e.g., among departments, divisions, units, schools, clusters of schools)

Figure 7. From Primary Prevention to Treatment of Serious Problems

Intervention Continuum	Examples of Focus and Types of Intervention
<p><b>Primary prevention</b></p>	<p>1. Public health protection, promotion, and maintenance to foster opportunities, positive development, and wellness</p> <ul style="list-style-type: none"> <li>• economic enhancement of those living in poverty (e.g., work/welfare programs)</li> <li>• safety (e.g., instruction, regulations, lead abatement programs)</li> <li>• physical and mental health (incl. healthy start initiatives, immunizations, dental care, substance abuse prevention, violence prevention, health/mental health education, sex education and family planning, recreation, social services to access basic living resources)</li> </ul>
	<p>2. Preschool-age support and assistance to enhance health and psychosocial development</p> <ul style="list-style-type: none"> <li>• system enhancement through multidisciplinary team work, consultation, and staff development</li> <li>• education and social support for parents of preschoolers</li> <li>• quality day care</li> <li>• quality early education</li> <li>• appropriate screening and amelioration of physical and mental health and psychosocial problems</li> </ul>
<p><b>Early-after-onset intervention</b></p>	<p>3. Early-schooling targeted interventions</p> <ul style="list-style-type: none"> <li>• orientations, welcoming, and transition support into school and community life for students and their families (especially immigrants)</li> <li>• support and guidance to ameliorate school adjustment problems</li> <li>• personalized instruction in the primary grades</li> <li>• additional support to address specific learning problems</li> <li>• parent involvement in problem solving</li> <li>• comprehensive and accessible psychosocial and physical and mental health programs (incl. a focus on community and home violence and other problems identified through community needs assessment)</li> </ul>
	<p>4. Improvement and augmentation of ongoing regular support</p> <ul style="list-style-type: none"> <li>• enhance systems through multidisciplinary team work, consultation, and staff development</li> <li>• preparation and support for school and life transitions</li> <li>• teaching "basics" of support and remediation to regular teachers (incl. use of available resource personnel, peer and volunteer support)</li> <li>• parent involvement in problem solving</li> <li>• resource support for parents-in-need (incl. assistance in finding work, legal aid, ESL, and citizenship classes)</li> <li>• comprehensive and accessible psychosocial and physical and mental health interventions (incl. health and physical education, recreation, violence reduction programs)</li> <li>• academic guidance and assistance</li> <li>• emergency and crisis prevention and response mechanisms</li> </ul>
	<p>5. Other interventions prior to referral for intensive, ongoing targeted treatments</p> <ul style="list-style-type: none"> <li>• enhance systems through multidisciplinary team work, consultation, and staff development</li> <li>• short-term specialized interventions (incl. resource teacher instruction and family mobilization; programs for suicide prevention, pregnant minors, substance abusers, gang members, and other potential dropouts)</li> </ul>
	<p>6. Intensive treatments</p> <ul style="list-style-type: none"> <li>• referral, triage, placement guidance and assistance, case management, and resource coordination</li> <li>• family preservation programs and services</li> <li>• special education and rehabilitation</li> <li>• dropout recovery and follow-up support</li> <li>• services for severe-chronic psychosocial/mental/physical health problems</li> </ul>
<p><b>Treatment for severe/chronic problems</b></p>	

Adapted from Adelman and Taylor (1993).

It is relatively easy to conceptualize a comprehensive package of interventions. It is excruciatingly hard to (a) establish such a range of programs, (b) integrate those that are in operation, and (c) conduct the type of research that advances understanding. The difficulty is exacerbated by the reality that addressing mental health and psychosocial concerns are not primary items on a school's agenda. This should surprise no one since schools are not in the mental health business. Their mandate is to educate. From that perspective, activities not directly related to instruction usually are seen as taking resources away from the school's primary mission.

Given this reality, initiatives aimed at directly and narrowly expanding physical and mental health activity in schools probably will continue to have a relatively low priority. Thus, in working with schools, it has been found more effective to approach mental health and psychosocial concerns from the broader framework of addressing barriers to development, learning, and teaching (Adelman & Taylor 1998, 1999); Center for Mental Health in Schools, 1996, 1997). This broader approach allows for encompassing a range of policy concerns and strategies designed to counter marginalization and enhance integrated collaboration between school and community resources.

Mental health in schools should not be viewed as a separate agenda from the instructional mission. In terms of policy, practice, and research, it is more fruitful to see mental health as embedded in the continuum of interventions that comprise a comprehensive, integrated component for addressing barriers and enhancing healthy development and learning. Once policymakers recognize the essential nature of such a component, it should be easier to weave together all efforts to address barriers and, in the process, elevate the status of programs to enhance healthy development.

“What we’re seeing in the school-based health centers are a lot of primary care providers for whom over 50% of their caseloads are children with psychosocial, not just mental health, problems.” *Linda Taylor, PhD*

## Prevention

The White House Conference on Mental Health (June 7, 1999) considered future directions in policy, practice, research, and training. The Administration's initiatives directly related to young people are to launch a national school safety training program for teachers, school personnel, and community members and expand the “Caring for Every Child” campaign (which identifies and supports children with mental illness). Other initiatives for enhancing response specifically to mental illnesses may affect youngsters (e.g., the emphasis on coordinated Medicaid services, outreach to the mentally ill who are homeless, responding to the mental health needs of crime victims, educating the criminal justice community to better prevent crime by mentally ill people and address the needs of offenders with mental illness, and more biologically-oriented research). As policymakers move toward action, there is an increasing focus on mental illness rather than a perspective of mental health that also encompasses wellness, prevention, and early-after-onset interventions—with an emphasis on psychosocial as well as biological factors.

“Prevention is just a dream.” There are a few prevention projects around the country, but there are no major systems of prevention in school districts and neighborhoods. *Mary Jane England, MD*

# Recommendations

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Many of the same issues facing conferees twenty years ago still plague us today. However, the increasing fragmentation of healthcare complicate the solutions to problems of access, integration, quality, and effectiveness of children's mental health services. The following recommendations formulated by the Children's Mental Health Alliance Project are directed to policymakers, managers, practitioners, researchers, and consumers.

## Policymakers

**Parity.** There is a need for universal coverage, including mental health benefits. Comprehensive mental health services for children and adolescents should be integrated into or coordinated closely with overall health care of children and families. This implies more than protocols and form completion.

Because child psychiatric disorders are recurrent, chronic and affect child and family functioning, they should be expected to require higher health care utilization. Provision for these services should be required in managed care plans.

**Coordination and a system of care.** Behavioral health care which serves Medicaid beneficiaries should be required to demonstrate coordination and a system of care. Agencies that respond to financial incentives to designate rather than assume responsibility for necessary care should anticipate penalties. Funding streams for children's mental health issues should be united, along with a consolidated, rather than categorical, system of care.

Special enabling programs must be a component of a system of care for complex and distinct sub-populations such as children with severe and persistent emotional/behavioral problems, multiply-disabled children with psychiatric disorders, children in foster care, or children of parents with serious mental illness or substance abuse disorders. Policy efforts should recognize different levels of solutions for those children who have minimal cf. moderate cf. severe problems. With improved care for severely affected children, resources can be better distributed to less affected children.

Because for-profit carve-outs encourage and reward the shifting of costs from their budget to public agencies, pediatric primary care providers, and schools, carve-outs should be re-evaluated in terms of the larger costs they may incur to society.

**Accountability.** Efforts should be hastened to create a uniform approach for gathering information concerning quality indicators, including some tracking and outcome of children's mental health problems. For example, potential consumers and managers should have access to information regarding how a health plan identifies children with mental health needs, the average number of visits for a mental health problem, percentage of children treated pharmacologically for a mental health concern. Accreditation standards related to quality, access to care, process and outcomes reporting are needed.

The responsibility of medical cf. school or social service agencies should be clarified and coordinated through interagency agreements using the best interest of the child as the major criterion. While cost sharing should be encouraged, ultimate fiscal responsibility must be clearly articulated.

**Need for research.** Health services research using the resources of public agencies, foundations, and managed care organizations should be part of the evaluation and contracting processes. Concrete tasks should include promoting comprehensive benefits at the state and national level, developing alliances that include medical professional and families, pushing for employer buy-in, and recognizing and funding preventive services in schools as community centers

## Consumers

**Community education.** Public information campaigns should be developed to educate consumers, de-stigmatize mental health problems, and stimulate patient activation.

- Consumers need to educate themselves about the options of care. Services for children with mental health problems should not consist solely of pharmacological interventions.
- Consumers should learn how to appeal denials of care and push to improve health and the quality of life, as well as address barriers to learning in the school and home.

**Family-centered care.** Stronger family support initiatives should include family representation in all aspects of children's mental health including policy, research, and training. This should result in:

- Consumer-driven innovative primary care and behavioral health models based in the schools and other accessible community settings (e.g., shopping malls, community centers, churches, and neighborhoods)
- Behavioral health programs should focus on a strength-based approach to family-centered care.
- Family leadership should be included on the governance boards of institutions, such as children's hospitals, community-based services, and advisory boards of the managed behavioral carve-outs.

## Managers

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**Quality assurance and standards of care.** The multiple stakeholders involved in children's mental health service need to agree on outcomes and quality indicators. National Committee for Quality Assurance standards regarding psychiatric screening, prevention, early recognition, and treatment should be developed and applied to children, including:

- A minimum set of mental health benefits, including all elements of necessary care defined to set the standard of care in the managed care industry
- Coordination of care as the shared responsibility of both the behavioral health carve-out and the parent managed care organization
- Participating providers trained and expected to implement behavioral interventions within this framework
- Optimal mental health service provision by primary care providers defined and disseminated with a clear mechanism for revision
- Cross-disciplinary training of all professionals who work with children regarding mental health issues

**Addressing barriers to evidence-based behavioral health.** An evidence-based approach to children's mental health problems is needed and must address the complexity of working with several levels of primary care providers as well as specialists. Practice guidelines should be produced that are presented in a user-friendly format, coupled with enabling tools (such as office facilitators and patient education materials that are consistent with the guidelines), supported by major medical societies, updated on a regular basis and widely disseminated. Practice guidelines for primary care providers should include criteria for referral. The use of practice guidelines needs to be evaluated on a regular basis to determine if they are being applied appropriately and to determine their impact on child outcomes and cost.

## Practitioners

**Responsibility for care.** Psychosocial dysfunction and psychiatric disorders are harmful to children. Health care providers who assume medical responsibility must provide the best care based on what is presently known so that children can fulfill their potential.

- Preventive and early interventions are needed to improve children's mental health. This should include increased support for parenting ages 0-5 years.
- Family support programs, including child support and broad support at work, have a significant impact on children. Family-based interventions are needed to prevent/identify risks or provide early interventions in domestic violence, physical and sexual abuse, family alcoholism and addiction, and parental depression.
- Practitioners should call for better demonstrations and critically review evidence of the effectiveness of children's mental health interventions.
- Each child deserves a healthy relationship with an adult, be it a doctor, teacher, case manager, parent, or nurse. The provider should identify and collaborate with this adult.
- Practitioners should appeal denials of appropriate health care.

**Delivery of mental health services.** Children need to be evaluated in the context of their families, ethnicity, communities, and environments, incorporating:

- Accessible services for individuals with limited English proficiency (Cultural and language interpreter services should be retained when needed.)
- Enhanced quality and comprehensiveness of care with an emphasis on increased continuity of care
- The model of a medical home including schools, community, as well as traditional medical homes
- Collateral work with families and parents beyond basic parenting classes to the recognition of and increased education regarding various behavioral and developmental problems
- An increased family role in clinical service delivery, including use of peer educators and parents as case managers and treatment facilitators

#### **Service integration**

- Specialty care practitioners need to feedback clinically relevant information on diagnosis and management of children with mental health disorders to their primary care practitioners (This should include detection of misdiagnosis, detection of co-occurring disorders, change in medication or the need for family based intervention.)
- A consolidated system of care is needed whereby involved agencies work together and interdisciplinary communication, training, and treatment planning occurs on a regular basis.

## **Researchers**

Research in children's mental health services should be the shared responsibility of health care, managed care and academia.

**Efficacy.** The limited evidence about the efficacy of psychotropic interventions for children is hindering development of an evidence-based approach to children's mental health. Several research initiatives are underway addressing efficacy of psychotropics, or multimodal treatments. More efficacy trials including children are needed. Studies of combined pharmacotherapy are needed to determine under what conditions multiple psychotropic medicines are indicated. Whether early identification of behavioral symptoms at the sub-threshold level would lead to better prognosis or outcome needs to be explored. Thus, evidence is needed to support the contention that mental health interventions in childhood produce better outcomes in adolescence or adulthood.

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**Effectiveness.** The limited evidence about the effectiveness of primary versus specialty care for children's mental health services will lead to further variation in the provision of these services and uncertain outcomes. The study of "usual care" and mediators in real life settings is essential in assisting the translation of research into practice.

- Health services research should compare outcomes of care provided under a variety of delivery models, including co-management, and alternative modes of care, such as school-based clinics or services.
- System level characteristics, such as availability and coordination of services, managed care features, cultural sensitivity, family function and involvement may modify the effectiveness of any specific intervention. These system factors should be considered as effect modifiers for studies of the primary care/specialist interface and require careful study design.
- The impact of parental education, intervention and involvement as well as family based interventions on child mental health outcomes needs to be demonstrated, and specific indications for such interventions need to be derived.
- Effectiveness studies should include how treatment processes and quality improvements approximate practice guidelines and what impact these processes and guidelines have on outcomes and costs of children mental health services.

**Dissemination.** Specific and timely means of disseminating the results of efficacy trials and effectiveness studies to primary care and specialty care providers is necessary in order to address the gap between research and practice for both primary and specialty care providers. Creative ways of keeping primary care up to date are needed.

**Multidisciplinary approaches.** Research should be interdisciplinary and collaborative, incorporating medical disciplines (including pediatric primary care providers, family physicians, psychiatrist, and psychologists) and the extension of those medical disciplines into the community including families, schools and the community as a whole. In order for the research team to be culturally competent and relevant to the community, family members of children who are being studied need to be fully integrated into the research process. Research needs to incorporate multiple perspectives, including those of the family and the consumer.

**Methods and measures.** Measures of function, outcome, quality, readiness for change, parental and familial function, medical cost offset, and systems coordination need to be developed in order to capture the complexity of the multiple factors that contribute to child mental health. A consensus regarding a set of functional outcome measures (such as school attendance, parental job function) is needed. The sensitivity and specificity of screening instruments in primary care settings will need to be determined. The outcome of screening in primary care settings needs careful evaluation and follow-up to determine cost-effectiveness. The measures for describing the long and short-term cost effectiveness of children's mental health services need to be developed.

**Long-Term Outcomes.** Research needs to move beyond short-term assessments, such as those used in typical efficacy trials, on to demonstrating the impact of early identification, prevention and intervention services in the primary care. Longitudinal epidemiological data on the outcome and prognosis of childhood psychiatric disorders are needed in order to guide childhood treatment strategies. Long-term studies of the impact of early intervention on the evolution of childhood mental health prob-



lems and adult psychiatric disorders are needed to gauge the impact of childhood mental health services on adult mental health and productivity. Primary prevention studies with long-term outcomes are also needed to guide the design and implementation of prevention efforts in primary care.

# A Historian's View from the Future

Rosemary Stevens

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While this consensus process continues to examine evidence-based medicine, statistics, and research, it is important that the power of stories is not forgotten. From a historian's perspective, the use of stories remains a potent way of framing what is in many ways a political process of advocating, appealing for research funds, and of getting the message out.

Invent a story then, and speculating about what the late 1990s and the year 2000 might look like from sometime in the future, what one might see in the longer term. One might see the following:

- Changes in the health care system
- Changes in professional status and prestige
- Reinvention of the science base for children's mental health
- General changes in primary care

In terms of our *health care system*, how might this period look? We could imagine one scenario in which managed care settles down into a relatively stable competitive system instead of the constant change we have been experiencing. In this scenario, managed care would be regulated at both the federal and state levels into a system of regulated public utilities. So, there might be more stability in the health care system, making it much easier to conduct long-term prospective epidemiological and outcome studies. Of course, another imaginable future is equally possible: market place enthusiasm wanes, the government is "rediscovered" and once again becomes a more important player in the organization and financing of health care. Certainly, in the early 1970s many people said, "National health insurance is around the corner." And, in the early 1990s, one might have claimed that health reform was definitely going to succeed. We may be equally biased today in assuming that the market is going to be the single dominant engine for change in the long-term future. If national health insurance does occur, perhaps this time led by the medical profession, other health professions and employers, concerns in the field of mental health might shift back to relations with government, rather than negotiating with market driven entities as at present.

In any of these scenarios, the more regulated stable market scenario or an increased role for government, or both at the same time, the *health professions* may be able to exert greater authority than they do right now. In the last few years, there have been evident problems of professional status, prestige, and great change in terms of incomes, the job market, and the stability of hospitals and medical schools. In terms of professional status and prestige, there are two conflicting movements, the managed care revolution and the concerns about an oversupply of health professions. Additional concerns center on increased work to be done in a shorter length of time, especially in relation to complex diagnoses and treatment regimens. These concerns may well be viewed from the future as part of the discomfort of transition to practice within organizations, transition that has been long overdue. Some organizational correction has been necessary and evident for at least 50 years. The question is how will

relations between the health professions and organizations be negotiated now? Who is setting the practice guidelines and what is going to happen to those guidelines through the organizational structure? Will it be possible to demonstrate commitment to the new organizational order as it changes through responsible professionalism? Power may be expressed in very different ways in the development of collaborative relationships between health professions, managed care organizations, and health care systems; it may actually accrue to each, since power is not a finite entity.

I believe this may be a great opportunity to look forward to enhanced opportunities for health professions, whatever the future structure of the health care system might be. The outcome of this particular period—our present—may be particularly important to what happens next and what may happen in the longer term. When there is change, there is opportunity to create change, to demonstrate improvements in the care of children. Achieving consensus across diverse groups that traditionally battle with each other is difficult but is vital to this era. Consensus building is needed regarding what is optimal treatment in the care of children and adolescents, defining the special competencies of mental health professionals at different levels, and the value to be placed on quality in the marketplace.

In terms of the *reinvention of the science base* for children's mental health, it is important to ask, "Who is doing evidence-based medicine?" If the health care professionals and researchers are not going to do it, who is going to do it? The answer is, "It is not going to be done." Managed care is not going to do the same kind of studies as health care professionals and researchers will. The most interesting aspect of the changing science base in mental health is the opportunity to do not just outcomes research, drawing on available methods, but also to develop biopsychosocial research. There have been tremendous advances in pharmacology but, at the same time, there is a very striking lack of information across the board about the epidemiology of mental health problems among children and adolescents, the experiences of those children and the experiences of the clinicians treating them.

These changes are linked to the *changes in primary care*. Primary care has been the most intellectual, interesting, and engaging part of medicine. And yet, the primary care specialty fields have not been recognized as being at the forefront of the intellectual science base of medicine. Hopefully, this is an opportunity to change.

This is an exciting time. This project is working across disciplinary boundaries not only in terms of the content of the field but also in terms of the professional aspects of the field. This project is probing into what works and what does not work, offering a much greater and more practical plan than has been seen before. There is a strong desire to "do something," which suggests there really will be change. Leaders of the professional groups and individuals in the professions are seeing the need to seize authority before it is too late. All of the professional associations are talking about quality, competence, outcomes, and evidence-based medicine. Now is the time for leadership in this field. Now is the time for positive thinking. Now is the time for getting things done for constructive change in the field of mental health for children and adolescents.

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