



Data Trends

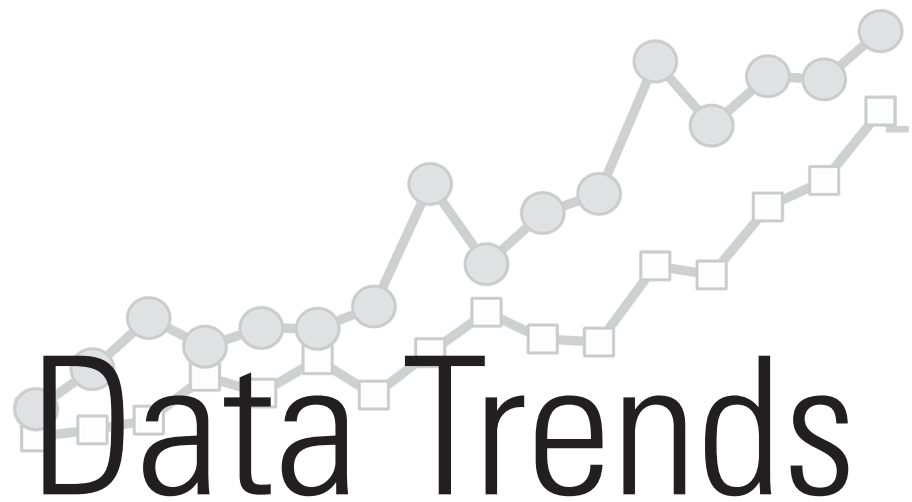
Summaries of Current Research Findings
in the Children's Mental Health Field

issues number 1-16
december, 1999

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Data Trends are produced to increase the dissemination of current research findings in the area of children's mental health services. Each issues of *Data Trends* summarizes, in a single page, a current publication in the children's mental health area to alert the field to current findings and activities. A citation is given for each summary so the readers will be able to retrieve the original document for further examination.

The enclosed *Data Trends* were produced by the Research and Training Center for Children's Mental Health in Tampa, Florida.

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Source: Rosenblatt, A. (1998). Assessing the child and family outcomes of systems of care for youth with serious emotional disturbance. In Epstein, M. H., Kutash, K., & Duchnowski, A. (Eds). *Outcomes for children and youth with behavioral and emotional disorders and their families*. Austin, TX: Pro-Ed, pp. 329-362.

This 1998 chapter by Abram Rosenblatt provides one of the best summaries of studies on the effectiveness of community-based systems of care. This chapter provides a very thoughtful discussion of the issues involved in conducting such evaluations, and builds on an earlier review done by Beth Stroul (1993).

The chapter begins by presenting a set of domains for describing outcomes. Essentially, the five domains that are used are: clinical status; functional status; life satisfaction/fulfillment; safety/welfare; and cost/utilization of services. Rosenblatt makes the point that unless we use such a framework, we run the risk of aggregating findings that should not be combined.

Rosenblatt then reviews outcomes of 20 community-based systems of care. Not all studies report data in each outcome domain. However, Rosenblatt reports improvement on clinical status in 8 of 9 studies, and in functional status in 10 of 11 studies. The only study for which no difference was found on both clinical status and functional status was the Fort Bragg evaluation. Rosenblatt reports six studies that have measured life satisfaction or fulfillment. The results are very positive in all six studies, including Fort Bragg in which satisfaction was higher than in the comparison group.

In the safety and welfare area, Rosenblatt reports reductions in either arrests or use of detention in four of four studies, and improvement overall in a fifth study. In the cost utilization area, positive results are obtained in 17 of 18 studies. These positive results reflect either reductions in the cost of care, or reductions in the utilization of restrictive levels of care as measured through hospital admissions, inpatient lengths of stay, state hospital expenditures, or residential treatment center placements. The one exception is Fort Bragg, where costs were greater in the demonstration than the comparison site.

While these results are very encouraging, Rosenblatt points out that, “the existing research on systems of care is extremely difficult to evaluate critically. Most studies are not published in scientific journals and thus are not subject to peer review; descriptions of methodology are generally inadequate; and statistical analyses are often either inappropriate or incomplete.” He also points out that most studies simply used a pre-post design without any comparison group, and that the one study with the least positive results (Fort Bragg) had a comparison group and had a strong design.

While Rosenblatt calls for more and better studies, he also concludes that:

- Across a range of outcome domains, youth with serious emotional disturbances who are enrolled in innovative systems were found to show improvement; and
- With the exception of the Fort Bragg study, the research demonstrates that systems of care can manage costly out-of-home placements.

Rosenblatt indicates that the research methods for those studies examining out-of-home placements was actually stronger than the methods for those studies assessing outcomes on other domains, increasing the strength of the conclusion that “communities implementing systems of care can control residential placements (either lower or reduce the rate of increase).”

Source: Zametkin, A. J., & Ernst, M. (1999). Problems in the management of Attention-Deficit-Hyperactivity Disorder. *The New England Journal of Medicine*, 340(1), 40-46.

This recently published article provides an excellent review of the management of ADHD, particularly for medical practitioners. The presence of this article in *The New England Journal of Medicine*, through the journal's prestige as well as its targeted audience of general medical practitioners and medical researchers, provides evidence that issues in children's mental health treatment are of increasing interest and priority. Zametkin and Ernst provide a concise review of diagnostic, treatment, and clinical issues characterizing Attention-Deficit-Hyperactivity Disorder (ADHD).

With regard to diagnostic issues, the authors note that a diagnosis of ADHD can be made as early as age 3, but the validity is questionable. Because the parent of a child with ADHD has an increased risk of also having the disorder, the importance of obtaining a family history is emphasized. Such a circumstance, the authors point out, may have implications for treatment compliance, as a parent who is inattentive or impulsive "may be highly inconsistent in following treatment recommendations." A complete medical history and physical examination as well as hearing and vision assessments are critical to the diagnostic process. Other evaluation procedures, such as neuropsychological testing and brain imaging, are quite costly and often inappropriate for routine evaluation. Psychometric testing is highly recommended when evidence of learning difficulties exists as the two conditions aggravate each other.

The authors continue with a discussion of the benefits and limitations of the various components of multimodal treatment for ADHD (please see figure). Non-medical interventions are given brief attention, and it is apparent that the medical model prevails in this article. This emphasis is exemplified by their review of data on the efficacy of stimulants. While the data indicate that on-task behavior, completion of academic tasks, and social competence increase with the use of stimulants, long-term academic achievement has not been documented. Thus, "stimulants have not been proved to remedy all conditions associated with ADHD."

The authors advise physicians on a number of clinical issues, including effective dosing regimes, the persistence of symptoms in adolescence and adulthood, attending to parental concerns related to increased risk of substance abuse, and unproven treatments such as dietary restrictions, biofeedback, and megavitamin therapy. To the authors' credit, poor treatment implementation is cited as a primary reason for treatment failure in both medical and non-medical interventions.

Multimodal Treatment in the Management of ADHD:

- ☐ Education, support, and empowerment of parents and youth
- ☐ Behavior-modification techniques (i.e., positive reinforcement)
- ☐ Educational interventions for those with learning problems
- ☐ Social skills training in naturalistic group settings
- ☐ Individual counseling to alleviate secondary symptoms (e.g., low self esteem)
- ☐ Medical intervention

Much debate surrounds the use of stimulants in the treatment of ADHD, particularly given the eightfold increase in their use in the United States over the past decade. While the authors state that "overdiagnosis remains a matter of concern," they indicate that the rise may be due to increased public awareness resulting in evaluation referrals, the continuation of treatment from childhood into adolescence, and the treatment of adults. Despite the reluctance of many parents of school-age children to use medication as a treatment option, the authors assert that physicians have the responsibility to inform parents of the potential benefits of treatment and possible negative consequences of nontreatment.

Given its apparent increasing incidence, Zametkin and Ernst's recommendations for further genetic and pharmacologic studies and continuation of evaluations of multimodal interventions are quite justified.

Source: Walrath, C. M., Nickerson, K. J., Crowel, R. L., & Leaf, P. J. (1998). Serving children with serious emotional disturbance in a system of care: Do mental health and non-mental health agency referrals look the same? *Journal of Emotional and Behavioral Disorders*, 6(4), 205-213.

Understanding the characteristics of the children and families served in systems of care is vital to effectively matching services to needs. Using data from the East Baltimore Mental Health Partnership (EBMHP), one of the CMHS Child Mental Health Services Initiative demonstration sites, Walrath et al. report the findings of a study comparing the characteristics of children referred to the EBMHP by a traditional mental health center and those referred by education, juvenile justice, and social services.

Data were gathered on the demographics, psychosocial histories, functioning, and diagnoses of 254 children and their families referred to the EBMHP by one of the four agencies. Overall, the children referred to the EBMHP were predominately African American (93%), male (69%), and had an average age of 11 years. Over half lived alone with their mothers, and more than 2/3 came from families with reported annual gross incomes under \$10,000. With regard to referral patterns, education referred 36% of the children, followed by mental health (26%), social services (22%), and juvenile justice (16%).

Results indicated that children from different referral sources had different profiles. For example, children referred by the mental health agency tended to be males presenting with problems of physical aggression, significant levels of psychosocial dysfunction, internalizing problem behaviors, and oppositional defiant disorders, while those referred by social services were predominately females of late elementary school age characterized by histories of physical aggression, depression, and adjustment disorders. Such a finding, the authors assert, has important implications for service and practice. For instance, the needs of the children referred by the mental health agency were met through home-based services and the development of a strong coordination among outpatient, emergency room, inpatient, and respite services. Due to issues of reunification and placement stability, a strengths-based approach was particularly important for those referred by social services who typically received case management and mental health services as well as parent advocacy training and support.

In addition to implications for the design and delivery of services, these differing profiles “lay the empirical groundwork” for conducting analyses in an attempt to better understand differential outcomes as a function of subgroup for those served in systems of care. This latter implication is particularly important given attempts to determine which children and families “could, would, and do benefit most” from a system of care approach to service delivery.

Walrath et al. conclude that “children in need of mental health services do not constitute a homogeneous group.” This finding is consistent with that of other recent studies (e.g., Rosenblatt et al., 1998) indicating that despite sharing a common label of *serious emotional disturbance*, children served in a system of care may not share common mental health profiles.

Source: Rosenblatt, J. A., Robertson, L., Bates, M., Wood, M., Furlong, M. J., & Sosna, T. (1998). Troubled or Troubling? Characteristics of youth referred to a system of care without system-level referral constraints. *Journal of Emotional and Behavioral Disorders*, 6(1), 42-64.

In one of the first articles presenting site-specific findings from a CMHS-funded demonstration site, Rosenblatt and her colleagues present data from the Multiagency Integrated System of Care (MISC) in Santa Barbara County. The authors classified youth based on risk factors and emotional/behavioral characteristics and examined whether different agencies referred youth with different profiles.

Participants (N=128) were predominately Latino, male, and had an average age of 14 years. Most were referred to the MISC by probation agencies.

Results indicated that different agencies referred youth with different profiles. For example, youth referred by probation agencies tend to be older, experience problems in the community, have moderate problems with substance use, low problem behavior scores, moderate to high risk factors, and a high number of arrests. In contrast, those referred by mental health tend to be younger, have higher behavior problem scores, no arrests, fewer risk factors, moderate problems in the home, and few problems in the community and with substance use.

Perhaps the most significant finding was the identification of four types of youth:

- | | |
|---|---|
| <input type="checkbox"/> Troubled | Primary problems in emotional functioning |
| <input type="checkbox"/> Troubling | Primary problems in delinquency and related behaviors |
| <input type="checkbox"/> Troubled and Troubling | Combination of both types of problems |
| <input type="checkbox"/> At-Risk | Multiple risk factors but less severe problems |

While all agencies referred youth across these four groups, probation agencies tended to refer more youth with “Troubling” and “Troubled and Troubling” profiles, while other agencies were more likely to refer youth in the “Troubled” cluster.

These findings address the longstanding debate as to whether services should be provided to youth considered socially maladjusted (“Troubling”) versus those with serious emotional problems (“Troubled”). Identification of the “Troubled and Troubling” profile provides strong evidence that youth can experience social maladjustment and serious emotional disturbance (SED) and that those with social maladjustment should receive special education services.

Further, these findings suggest that particular service delivery approaches may be more effective with specific types of youth depending on age, ethnicity, risk factors, behavioral characteristics, and level of functioning. The authors are to be commended for their efforts to demonstrate the potential utility of a classification system for youth. Such a system may help to more precisely tailor services to meet the unique needs of particular types of youth within systems of care.

Source: Rosenblatt, J. A., & Furlong, M. J. (1998). Outcomes in a system of care for youths with emotional and behavioral disorders: An examination of differential change across clinical profiles. *Journal of Child and Family Studies*, 7(2), 217-232.

The authors report preliminary findings for youth served in the CMHS-funded Multiagency Integrated System of Care (MISC) in Santa Barbara County. It is one of the first publications to present site-specific outcomes.

The article presents results for 87 youth for whom 6-month follow-up data were available. Almost three-quarters of the youngsters were boys, the average age was 13.7 years, and the group was ethnically diverse being 43% Latino, 38% Caucasian, 16% African American, and 3% Asian American. Two-thirds were referred to the MISC by probation agencies.

Building on their earlier work, Rosenblatt and Furlong divided referred youth into four groups, based on individual risk factors, number of prior arrests, CAFAS scores, and CBCL scores:

- | | |
|---|---|
| <input type="checkbox"/> Troubled | Primary problems in emotional functioning |
| <input type="checkbox"/> Troubling | Primary problems in delinquency and related behaviors |
| <input type="checkbox"/> Troubled and Troubling | Combination of both types of problems |
| <input type="checkbox"/> At-Risk | Multiple risk factors but less severe problems |

The authors made this distinction because they believed the results of studies that combine the outcomes of all youngsters may produce misleading findings. They hypothesized that progress should be expected mainly in the area of greatest need as treatment would primarily target areas of major concern.

Significant progress was found on at least one outcome measure in all groups, except for the at-risk group, which had only nine youngsters and whose scores at entry into treatment were within the normal range. This overall positive result is encouraging, although, as the authors point out, their sample sizes were small, there was the possibility of regression to the mean, and they had no comparison group.

The authors also found partial support for their prediction that progress would likely occur in the area of greatest need. While youth in each group did improve in different areas, these differences were not significant.

Perhaps the most encouraging finding was that the two oldest groups and the two groups most involved in delinquent activity ("Troubling" in which the average age was 15.2 years and "Troubled and Troubling" in which the average age was 14.4 years) showed significant improvement on the CBCL Total Problem Scale and the CAFAS Total Problem Scale. While the study had a number of limitations, as already indicated, this finding remains encouraging because, as the authors assert, "the majority of research...suggests juvenile delinquents are not amenable to treatment." The study also helps make a case for assessing outcomes for youth based on a system of classification, rather than combining them into one group.

Source: Jerrell, J. M. (1998). Utilization analysis for children's mental health services. *Journal of Behavioral Health Services & Research*, 25(1), 35-42.

This article describes child and adolescent consumers of mental health services in South Carolina and the cost of these services for the 1994-95 fiscal year. The author also presents a methodology to isolate the relatively few people in a group who generate very high service expenditures. The study accomplishes two goals: it provides helpful data on mental health service expenditures in South Carolina, and it proposes ways that a database can be used by mental health administrators to highlight and better serve youths requiring extensive costly care.

Data for all child and adolescent consumers was obtained from the State Department of Mental Health, and represents use and cost data from 10 inpatient facilities and 17 community mental health centers. Youth served during this period ($N=22,100$) were separated into three cost groups: high, medium, and a low cost group. The number of youths and costs associated with each group are presented in the table below:

Cost group	Total cost	Mean \$ per child	# of youths	% Total cost	% of cases
Low	\$8 million	\$ 457	17,696	30%	80%
Medium	\$7 million	\$ 2,147	3,318	26%	15%
High	\$12 million	\$10,751	1,105	44%	5%

As indicated in the table, 5% of youth accounted for 44% of the total cost of mental health services for children and adolescents in South Carolina. Youth in the high cost group tended to be adolescents, referred by other service sources such as juvenile justice, to have Medicaid coverage, and to have serious mental health problems (i.e., psychotic, post-traumatic stress disorder, depression, and behavioral problem diagnoses). High cost youth had a higher percentage of previous inpatient stays, received more outpatient services, more structured day services, and more case management. Inpatient care was determined to be the "most significant driver of total service costs" for these children and youth.

The author's findings highlight the usefulness of computer databases for isolation of high cost children and adolescents to equip mental health administrators with additional information to evaluate community-based care and to "determine whether additional utilization management techniques or local program development are necessary."

Source: Burns, B. J. (1999). A call for a mental health services agenda for youth with serious emotional disturbance. *Mental Health Services Research*, 1(1), 5-20.

In this article, appearing in the inaugural issue of *Mental Health Services Research*, Barbara Burns makes an urgent call for the development of a research agenda on mental health services for youth with serious emotional disturbance. This proposal comes on the heels of the National Institute of Mental Health (NIMH) National Advisory Mental Health Council report on adults with severe mental disorders issued in 1991. This report led to a research plan and significant expansion of services research for this adult population. Burns believes a focus on the needs of children with severe disorders is long overdue and argues that “it is time to engage in a similar effort for children.”

Burns provides both a strong rationale and a comprehensive approach for developing the research agenda. The rationale is based on three key issues. First, Burns asserts that the need for effective treatment is “real,” given the considerable evidence of unmet needs, inappropriate care, and poor outcomes consistently documented for this population. Second, the author contends that “the time is right” for the development of a research agenda for children and youth. In addition to an expressed commitment to children and families at the federal level, as evidenced by such policy changes as the reauthorization of the Individuals with Disabilities Education Act and the National Institute of Justice’s search for alternatives to juvenile justice, Burns urges that children’s issues be given equal attention as those of adults. Finally, she argues that the knowledge base on what works in children’s mental health has expanded considerably, and there are researchers who have the expertise and interest needed to study the effectiveness of children’s mental health services.

In detailing the necessary steps for developing the research agenda, Burns recommends that NIMH or another agency commission an expert panel to address the following tasks:

- Conduct a review of promising clinical interventions for youth with serious emotional disturbance
- Assess the adequacy of existing tools for monitoring the quality of care (e.g., measures of treatment fidelity, best practices)
- Evaluate the adequacy and need for further development of outcome measures, particularly those that measure functioning
- Reach consensus on an appropriate research phase model, that is, determine the most appropriate research design for examining effectiveness

The expert panel should integrate their findings into a research plan and develop strategies for implementing the plan. Burns is hopeful when she states that “a research plan for youth with serious emotional disturbance could be endorsed before the new millennium.”

Specifically, as she briefly reviews the effectiveness research, Burns makes several important points. First, she points out that the Fort Bragg study, the Starke County study, and the review of outpatient services by John Weisz all “cast doubt about the value of usual care as provided in the community, and have suggested a need to look more carefully into the issues surrounding quality.” While Burns’ interpretation of the significance of these studies may be open to question, there is wide consensus about her conclusion of the “need to examine the relationships between service system characteristics, specific clinical interventions (including the fidelity with which they are implemented), and outcomes. Studies that look only at system-level inter-

continued...

ventions without looking also at the actual services and supports that are provided are likely to miss the mark, according to this view. Burns goes on to indicate that the research base is relatively strong for multisystemic therapy and therapeutic foster care, “is building for wraparound,” and remains weak for case management, family preservation, and group homes.

A major need that Burns identifies is tools for monitoring quality of care, including treatment fidelity. She does an excellent job of describing six approaches to deriving and implementing quality: 1) best practices, including CMHS “Promising Practices” series; 2) practice parameters for diagnostic-specific interventions that are either evidence-based or consensus-based; 3) regulations, largely for licensure, accreditation, or reimbursement by regulatory agencies; 4) quality monitoring, usually developed by clinicians to monitor clinical practice; 5) clinical protocols/manuals, historically designed to assure adherence to specific types of treatment; and 6) use of fidelity/adherence measures (primarily used in multisystemic therapy and therapeutic foster care but increasingly in wraparound).

Interestingly, in discussing research models for effectiveness studies, Burns goes beyond randomized clinical trials. While she sees randomized clinical trials as being critical for efficacy tests, she is supportive of the use of “observational designs” for effectiveness studies. She indicates that the advantages of such uncontrolled observational studies include more flexibility, less intrusion, greater ease in obtaining larger sample sizes, and lower study costs. However, she indicates that these uncontrolled observational studies include more flexibility, less intrusion, greater ease in obtaining larger sample sizes, and lower study costs. She indicates that these uncontrolled observational studies are particularly helpful where there have been good efficacy studies and where the results of the observational studies can be compared to the results of the efficacy studies. This is much easier to do with studies on the treatment of ADHD or phobias than it is with the treatment of youth with serious emotional disturbance through wraparound, for example.

Overall, this article is especially significant because it is a major part of the first issue of a significant new journal, includes a strong call for a research plan for children with serious emotional disturbance and their families, is written by perhaps the most respected overall researcher in the field, and includes excellent, although brief, summaries of many important issues.

Source: Hodges, K., Doucette-Gates, A., & Liao, Q. (1999). The relationship between the child and adolescent functional assessment scale (CAFAS) and indicators of functioning. *Journal of Child and Family Studies*, 8(1), 109-122.

This article summarizes changes on the Child and Adolescent Functional Assessment Scale (CAFAS) for those youth who had six months of uninterrupted service in sites across the country participating in the Center for Mental Health Services' *Comprehensive Community Mental Health Services for Children and their Families Program*.

Of the 3,187 youth for which information was collected upon entry, approximately two-thirds (64.3%) of the youth were males with an average age of 11.87 years, with the average age for girls being one year older. The majority of the families were impoverished, with 65% living below poverty level.

Analysis of CAFAS data at intake revealed that those youth who had previous psychiatric hospitalizations had higher CAFAS scores (i.e., were more impaired) than youth who had no previous psychiatric hospitalizations. Likewise, youth who lived in residential facilities were more impaired than youth who lived at home or in home-like settings. This was true for youth who lived in residential facilities at intake as well as for youth in residential facilities six months after entry into the program. Youth who performed below average academically were also found to be more impaired than youth who were performing at or above average academically. The same pattern was revealed in the area of contact with law enforcement. Youth who had contact with law enforcement were more impaired, as measured by the CAFAS, than youth who had no contact with law enforcement. The authors contend that these results support the CAFAS in determining functioning levels of youth across a variety of domains.

Ethnicity:	64%	Caucasian
	18.9%	African American
	8.4%	Hispanic
	8.7%	Other
Residence:	54%	Single parent families
	22%	Two parent families
	9%	Non-parental guardian
	12%	Wards of the state
	3%	Other
Referred by:	21%	Schools
	19%	State social services
	19%	Mental health
	14%	Parents
	9%	Juvenile justice
	18%	Other (public health, private physician, self)

A total of 873 youth had a CAFAS score at intake and again at six months post-entry. Analyses indicated that as a group, the total CAFAS score decreased significantly over the six months indicating improved functioning. No difference in rate of improvement was noted as a function of custodial status, referral source, previous psychiatric hospitalization, diagnosis, living arrangement, unsatisfactory school performance, poor attendance, or legal involvement. That is, regardless of these factors, all youth improved.

Source: Foster, E. M. (1998). Does the continuum of care improve the timing of follow-up services? *Journal of the American Academy of Child and Adolescent Psychiatry*, 37(8), 805-814.

Ensuring that children receive follow-up services after an inpatient stay is important for maintaining improvement and preventing readmission. In this article, Foster compares the timing of follow-up services for children ($N=216$) discharged from inpatient facilities at the Fort Bragg Demonstration site (i.e., continuum of care) with the Comparison site (i.e., traditional care).

This investigation was based on two assumptions. First, it was believed that the range of available services and the coordination of services provided within a continuum of care should increase the likelihood that follow-up services are received. Second, the individualized nature of care should strengthen the link between child and family characteristics related to follow-up service use.

Results indicated that both assumptions were confirmed. Individuals served at the Demonstration site were more likely to receive follow-up services when discharged from an inpatient facility than those at the Comparison site. In fact, the likelihood of follow-up service use at the Demonstration site was greater than 10 times that of the Comparison site. Findings also revealed that the timing of follow-up services was much more closely related to child and family characteristics at the Demonstration site. For example, individuals that exhibited more symptoms, had a caretaker who had been previously hospitalized, or who imposed a greater burden on their caretaker were more likely to receive follow-up services at the Demonstration site.

The implications of these findings are far reaching. They suggest that coordination of care and the availability of a continuum of services can influence continuity of care. He suggests that “children do not receive services when the families in which they live are overtaxed,” even when a wide array of services is available. Supplying families with needed resources may ensure that children return for follow-up care.

While these findings are positive, Foster asserts that a “full interpretation” would require additional studies investigating the impact of follow-up services on mental health outcomes and future service use. In addition to the characteristics examined in this study, we need a better understanding of other factors that influence the use of follow-up services.

Source: Halfon, Neal & Paul W. Newacheck. (1999). Prevalence and impact of parent-reported disabling mental health conditions among U.S. children. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38(5), 600-609.
E. Jane Costello. (1999) Commentary. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38(5), 610-613.

A set of two articles on prevalence and impact of mental health conditions among children in the United States is likely to promote a lively discussion. The main article, by Halfon and Newacheck, reports prevalence rates based on reports by parents who participated in the National Health Interview Survey in 1992, 1993, or 1994. Altogether, this involves 99,513 parents. The second article is a commentary by Jane Costello on the findings from the larger study.

Parents were first asked if their children experienced a long-term “disability” in their ability to perform their major social role. This major social role was defined as play for pre-school children, and attending school for school-age children. For those children who were identified as being disabled in performing that role, parents were then asked to give their perception of the reason for the disability. Using this approach, it was estimated that 2.13% of children under 18 years of age suffered from a “mental health condition” that resulted in a long-term reduction in the child’s ability to perform their major social role. The most common reported causes of disability were mental retardation, attention-deficit hyperactivity disorder, and learning disabilities, two of which are not typically considered an emotional or behavioral disorder. The estimate derived from this method is a much lower estimate than other estimates of “serious emotional disturbance.” For example, the CMHS report estimated that 9 to 13 percent of children between the ages of 9 and 17 have a serious emotional disturbance.

In responding to the article, Costello discredits the method used in the National Health Interview Survey. She suggests that, “Asking parents or adolescents to diagnose mental illness by choosing from a list of labels or brief descriptions is so far from producing a valid prevalence estimate that it has long been abandoned by psychiatric epidemiology... It does not seem unreasonable to expect that the NHIS approach, using a single informant and a very few questions, is likely to err in the direction of underestimating the prevalence of disabling childhood mental illness.”

Costello further points out that the definition of “disability” is also limited. It refers to only one area of functioning and would therefore exclude children whose disability is reflected in the home and/or in the community. With its focus on activity limitation, it also excludes students who are in special classes or in special schools, since they are attending schools. Also, the sample in the NHIS survey excludes children who are not living with their own family, a group for which there is likely to be a higher prevalence of disorders.

Costello does point out that a strength of the article by Halfon and Newacheck is their effort to gather information about the impact of illness. They do this by measuring the number of days in bed and the number of days absent from school due to the disorder. As Costello emphasizes, unfortunately these are narrow definitions of impact. “Impact or burden of child mental illness needs to be measured in ways that include its effects on the family such as inability to work or reduced hours worked, friction with family members, social restrictions, shame, and guilt.”

Despite the numerous methodological problems in the article by Halfon and Newacheck, it is likely to receive considerable attention because it was based on an extremely large national sample, and was published in a prestigious journal. If the results are taken seriously, it can cause policy makers to underestimate the need for services for children with emotional disorders and their families. Fortunately, the article is paired with a response by a distinguished researcher, and the response does an excellent job of pointing out the shortcomings of the original research.

Source: Geller, J. L., Brown, J. M., Fisher, W. H., Grudzinskas, A. J., & Manning, T. D. (1998). A national survey of "consumer empowerment" at the state level. *Psychiatric Services*, 49(4), 498-503.

This article presents data from what is believed to be the only existing study of the extent of consumer empowerment in the adult public mental health system. In an attempt to determine the role that state governments have played in the employment of consumers, the authors sent a questionnaire to mental health authorities in all fifty states and the five U.S. territories asking whether consumer empowerment or responsibility was defined in state statutes, regulations, or policies and whether consumers or family members were employed in central or field offices. A completed questionnaire was received from all states and territories.

The authors define consumer empowerment as "*clients' participation in treatment as collaborators with professionals and as the primary informants about what is needed from providers.*" The article also addresses the "empowerment" role that consumer advocate groups such as the Alliance for the Mentally Ill (AMI) play in mental health service delivery. In fact, 90% of state offices reported that the state mental health authority met regularly as well as on an as-needed basis with empowerment groups in their states, most often statewide or local affiliates of the AMI. "Consumer responsibility" is not defined and appears to be a term included in the questionnaire in the event that terminology varies among state policymakers; i.e., empowerment/responsibility to suggest consumer involvement. More states addressed consumer empowerment than consumer responsibility in state statutes, regulations, and policies; thus "empowerment" seems to be the more often used term in policymaking.

Using the information provided by each state, the authors rank-ordered each state on its extent of consumer empowerment. The extent of consumer empowerment was not related to region of country. Interestingly, a higher rate of state expenditures did *not* reflect an increase in policies covering consumer employment, while states with large populations and those whose mental health systems received favorable ratings from outside consumer advocate groups (such as the Public Citizen Health Research Group and the National Alliance for the Mentally Ill) were *more likely* to report consumer involvement.

Thus, while state expenditures were not associated with policy output, favorably rated state systems had higher rates of consumer involvement. The authors speculate that increased consumer empowerment, *sans* funding or policy, may be the result of : 1) larger tax bases that may generate more discretionary funds for consumer involvement, 2) larger consumer populations which provide greater opportunities for consumer involvement, 3) the likelihood that states valuing consumer involvement are also receptive to implementation of new practices, and 4) the influence of consumer employees on the day-to-day delivery of quality service and practices.

The authors call for future studies on how consumers in state or county mental health authorities influence policies, contribute to dialogue, and represent the consumer. Research, they suggest, should aim toward understanding if and how such policies and practices better serve the clinical needs of clients. Noting that this research is on adult consumers and family members only, we suggest that similar efforts ought to be made toward understanding connections between funding, policy, and consumer involvement for children's mental health care delivery systems.

Survey results

States and territories:

- | | |
|----|--|
| 22 | addressed consumer empowerment in statute, regulation, or policy |
| 16 | addressed consumer responsibility in statute, regulation or policy |

Percentage of paid positions:

- | | |
|-----|------------------------------------|
| 48% | consumers in central offices |
| 5% | family members* in central offices |
| 50% | consumers in field offices |
| 24% | family members* in field offices |
- * limited to those involving adult services

Source: Vander Stoep, A., Williams, M., Jones, R., Green, L., and Trupin, E. (1999). Families as full research partners: What's in it for us? *The Journal of Behavioral Health Services & Research*, 26(3), 329-344.

This distinguished research paper was first presented at the 1998 11th Annual Research Conference sponsored by the Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, Tampa. The authors highlight the 1998 King County Blended Funding Project as an innovative model for children's managed mental health care that signals a significant turning point in family support initiatives. Lessons learned from the King County Blended Funding Project suggest that participatory research and evaluation between researchers, parents, and parent advocates involved in children's mental health can have positive policy, research, and service outcomes.

The Blended Funding project was initially developed as a Mental Health Service Program for Youth (MHSPY) replication site funded by the Robert Wood Johnson Foundation. The project pooled funds from three sources: 1) a private, for-profit behavioral health company that manages the King County public mental health system in Washington; 2) the state managed, regionally administered child welfare system, and; 3) nineteen independent public school districts. Designed to "use managed-care tools to move the potential effects of good policy closer to their targets," *pooled funds were placed directly into the hands of community-based teams led by the child's family, a single-care manager, and a parent advocate*. Thus, funds flowed from system to family team to provider in order to overcome traditionally inflexible categorical service systems, fragmentation of financing and case management, and an otherwise hierarchical relationship between systems, providers, and families. Blended funds were used to purchase existing supports and to create supports that otherwise fall outside of categorical service boundaries, such as plumbing repairs and musical instruction.

Family contributions to participatory research:

- ❑ **Relevance.** Families know how to determine whether care is helpful and whether children are getting better; can help design research that yields meaningful knowledge.
- ❑ **Energy.** Families are passionate about learning what helps children. Designing a good evaluation is not an academic enterprise but may be a matter of life and death; this energy vitalizes research.
- ❑ **Validity.** Advocates believe that when parents interview other parents, they are able to elicit more candid responses to sensitive questions.
- ❑ **Skepticism.** Families can detect services, questions, and findings of questionable quality; they can help researchers correct faulty thinking.
- ❑ **Clarity.** Families motivate researchers to speak in language that is understandable to the general public. With effort and skill, families can help articulate even the most complex methodological concepts and research findings simply and clearly.

Outcomes included parent-to-parent interviews, family-driven research agendas, and parent advocate initiated theories of change. While the authors list some benefits of family participation (see box), it is important to consider that a major strength of the project lies in the fact that parents were given both the *opportunity and funding* to pursue their concerns side-by-side with researchers and other stakeholders in the project. Some outcomes were hard-won, as "many tensions [arose] between meeting the demands of both scientific rigor and multiple community stakeholders," but the move toward further collaboration looks promising: "As family members become less intimidated working within the traditional realm of the researcher, they recognize more fully the potential power of research to help families and the need for conducting well-designed studies to actualize this power." Likewise, research scientists come to "appreciate more fully the potential power of the community to strengthen research efforts and the need for strong community partnership to actualize this power."

Source: Farmer, E., Stangle, D., Burns, B., Costello, E. J., and Angold, A. (1999). Use, persistence, and intensity: Patterns of care for children's mental health across one year. *Community Mental Health Journal*, 35(1), 31-46.

This article reports on data from the Great Smoky Mountains Study (GSMS), one of the most important epidemiological studies to date on mental health service use by children and adolescents. The children and families participating in this study ($N=1,007$) were randomly drawn from 11 counties in western North Carolina (known for its well-developed mental health service system) and oversampled for children with emotional disturbances. The article reports on patterns of mental health care provided to children ages 9, 11, and 13 over a 12 month period ($N=1,007$). Of the population studied 51% were male, 27% lived below the poverty line, and 20% met criteria for a psychiatric diagnosis. The authors looked at one- and multiple-sector use, intensity of services according to need, and persistence of use.

Service use fell generally into two main categories: 1) school counseling provided by the education sector, and 2) non-intensive mental health treatment via public mental health centers or private professionals. The high percentage of education-sector treatment (see box) versus specialty mental health service use suggests that "coordination, especially with schools, is crucial for the provision of services." The younger children in this study were more likely to receive services through the education sector than were the older youths. Farmer et al. note that findings may underestimate school involvement in mental health services because data limited to children in the 9-14 year age bracket excludes a large portion of the primary and secondary population. Furthermore, data relied heavily upon parent reports of service use, and a "comparison of child and parent reports of school services suggest that reliance on parents may underreport use of school services."

Sector Providing Mental Health Services by Percentage of Children Receiving Services

Educational	12.0%
Specialty Mental Health	8.0%
Medical	4.0%
Juvenile Justice	0.8%
Child Welfare	1.4%
Informal, non-professional	4.0%

Children receiving services from two sectors were most often treated by both the educational system and as out-patients in the (public or private) specialty mental health sector. Three-fourths of all children receiving services from three or more sectors received services from the education sector, and in nearly all cases received services from specialty mental health services. The most common pattern of use was 1 to 2 visits over a 3 month period for both outpatient specialty mental health services and educational services. Very few in-home services, out-of-home placements, partial hospitalizations or specialized services for substance abuse were reported.

According to the authors, data from the first three months of the study revealed that only 40% of children with a serious emotional disturbance received any mental health services. Examining how children with serious emotional disturbances fared (e.g., whether they continued to receive mental health services) during a 12 month period was difficult to determine, due to a "complex pattern of movement into and out of services." However, the data speak to the need for children's increased access to specialty mental health services. Again, the region from which the GSMS data comes is known for its well developed mental health service delivery system. Yet the authors found that 60% of those children who met the criteria for a psychiatric diagnosis did not receive services within the first three months of the study. Data further indicates that of those children who did receive care throughout the year, symptomatology was most likely low-level and therefore treatable via school counselors and/or minimal out patient contact. Findings underscore the importance of interagency relationships between specialty mental health and other child-serving sectors (such as schools) to identify and treat children with both low- and high-level mental health services needs.

Source: Rosenheck, Robert A., M.D. (1999). Principles and priority setting in mental health services and their implications for the least well off. *Psychiatric Services*, 50(5), 653-658.

Instead of summarizing a recent research finding, this issue of *Data Trends* reports on an article that offers an interesting perspective on a complex and difficult issue that confronts mental health policy makers: given that resources for mental health services are not adequate to meet need, how should decisions be made about resource allocation? The article is selected not only because it addresses an important topic but because it does an interesting job of grounding this discussion in ethical theory.

In this article, Dr. Rosenheck, from Yale University, provides seven principles that “should, and often implicitly do,” shape resource allocation decisions (see box). The principles are not hierarchically ordered and in some instances will compete with one another. They are grounded in the ethical theories of the following philosophers: 1) moral imperativist Immanuel Kant, who argued for the autonomy of persons insofar as no one should be treated as a means to an end; 2) utilitarians Bentham and Mill, whose arguments for achieving the greatest good for the greatest number of people continue to influence current policy regarding cost-effectiveness; 3) social justice theorist John Rawls, who proposed that a just society, in order to be just, must provide a minimum standard of living for its least well-off citizens, and; 4) 1998 Nobel Prize winning philosopher-economist Amartya Sen, who further suggested that a just society must aid and encourage individuals to fulfill their potential.

Rosenheck extends the Kantian principle of autonomy beyond the individual to the involvement of local networks. His “responsibility of consumers” principle makes new use of cost-effectiveness concerns. This utilitarian-based principle may indeed clash with the principle of equity (reflected in the ideas of Rawls and Sen), and thus “It is here that the special obligation to the least well-off...emerges as important regardless of the relative cost and effectiveness of their treatment.” The potential to fulfill one’s capabilities seems to be a primary underlying principle for Rosenheck.

The *industry principle* encourages policymakers to look beyond marketing techniques and to “weigh the value of new treatments carefully and independently against existing treatments.” The final principle asks policymakers to carefully match existing community resources with funding. For example, a community having an active and effective local network of support may require less funding when balanced against a community requiring increased training for its paid health workers. Obviously, Rosenheck’s principles do not make policymaking any easier. But as a “framework of reference for understanding why priorities may legitimately vary and conflict,” they may help to clarify options and encourage “balanced and broad-based decisions” for resource allocation.

Principles Guiding Resource Allocation Decisions

- **Autonomy.** Attending to the needs of each individual patient should be considered to have absolute value.
- **Involvement of local networks.** Local networks of patients, providers, and other relevant stakeholders must have a voice in defining goals and priorities.
- **Maximization of benefit and minimization of cost.** Allocation of resources should maximize aggregate utility, or collective benefit, and minimize cost in terms of dollars expended per unit gain in health. Because all possible services cannot be provided to all patients, services providing the greatest improvement in health at the lowest cost should receive priority.
- **Equity.** Services should be provided fairly so that all people have access to services affording them a minimum standard of living and capability of fulfilling their potential.
- **Responsibility of consumers.** Clients must participate actively in their care and constructively in their programs. Priority should be given to patients who make good use of services that are offered.
- **Industry innovation and marketing.** Private corporations have unique incentives to develop and promote new technologies. Marketing efforts may promote new treatments in ways that inappropriately overshadow methods of care—typically psychosocial treatments—that are not commercially promoted.
- **Technical quality and skills of the local workforce.** Health care systems should be attentive to the best scientific research as well as to local population needs and provider skills.

Source: Wu, P., Hoven, C., Bird, H., Moore, R., Cohen, P., Alegria, M., Dulcan, M., Goodman, S., McCue Horwitz, S., Lichtman, J., Narrow, W., Rae, D., Reigier, D., & Roper, M. (1999). Depressive and disruptive disorders and mental health service utilization in children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38(9), 1081-1092.

Data for this article come from the largest multi-site epidemiological study to date on mental health service use by children and adolescents. Wu et al. looked at NIMH data gathered from the 1992 Methods for the Epidemiology of Child and Adolescent Disorders Study (MECA) to determine patterns of mental health service use by children and adolescents with disruptive and/or depressive disorders. The MECA Study is a probability sample of youths ages 9-17 who had used mental health or substance abuse services of any kind (e.g., through public or private mental health specialty services or through schools), and for a wide range of emotional or behavioral impairment, during 1991. Data were collected from four geographic areas in Georgia, Connecticut, New York, and Puerto Rico, total $N=1,285$.

The study conducted by Wu et al. makes a significant contribution toward understanding patterns of perceived need and service utilization for children and adolescents with emotional or behavioral disorders. Findings indicate that youths with disruptive disorders received treatment through both mental health services and schools, whereas youths with depressive disorders were more likely to receive treatment through schools only. Data thus underscore the need to identify and serve youths with depressive disorders. To this effect the authors (see box) suggest that school-based screening, combined with parent and teacher education, might be one avenue by which depressed children may receive treatment. Because previous studies reveal that depression is one of the leading causes of suicide in youth (Brent et al., 1993; Shaffer et al., 1996), the findings of this study are especially noteworthy.

After controlling for familial, parental, and individual characteristics, and by perceived child needs, the authors found that "children with disruptive disorders still appeared to be more likely to use mental health services than children without disruptive disorders." While mental health service utilization is often associated with demographic or parental factors such as ethnicity, child's age, and maternal mental health service use, Wu et al. report that such factors "have no effect on the use of school services." According to the authors, such findings are consistent with other studies which show that "school-based services are most widely used by children and adolescents and are easier to access (Burns et al., 1995; Flaherty et al., 1996; Lear, 1996; Staghezza-Jaramillo et al., 1995)." In fact, although youths with internalizing problems were less likely to be identified by others and to receive treatment for their depressive disorders, these children "actually reported more need for services than those with disruptive disorders." The authors suggest that if depressed youths already find a modicum of treatment through school-based counseling, it may be good clinical and policy practice to expand the role of mental health services in schools.

Clinical and Policy Implications:

"Our findings indicate that patterns of service use are influenced not only by sociodemographic factors but also by types of disorders. Among children and adolescents, depressive disorders are less likely to be identified than disruptive disorders. Consequently, children with depressive disorders are less likely to be referred to mental health professionals. In future service planning, policymakers and clinicians need to find more effective ways to identify and appropriately refer depressed children.

The findings of this study indicate the important role of school-based services in meeting children's needs for mental health services. School-based services provide an efficient locus for the cost-effective delivery of mental health services to children. Existing services should be improved and new services developed to meet children's unmet needs. For example, there is a need for school-based screening instruments to identify children's psychiatric disorders at an early stage.

Finally, parent's or teacher's perceived need for child mental health services plays a critical role in children's obtaining mental health services. Further mental health education should be offered to parents and teachers, which in turn will improve early identification and treatment of children with psychiatric disorders." (page 1089)

Source: Walsh, M. E., Brabeck, M. M., & Howard, K. A. (1999). Interprofessional collaboration in children's services: Toward a theoretical framework. *Children's Services: Social Policy, Research, and Practice*, 2(4), 183-208.

This theoretical article does an excellent job of advancing current discussions about interprofessional collaboration and has direct implications for the mental health field. The authors: 1) distinguish between cooperation and collaboration, 2) review various conceptual and practical barriers to collaboration, and 3) argue for the importance of a theoretical framework that can ground collaboration across professions. To this end, they propose a "biopsychosocial" life span model of development. Significantly, the authors also provide empirical evidence in support of interprofessional collaboration.

The biopsychosocial model assumes that development occurs across the life span, at multiple levels, and in context. Because professionals tend to identify themselves with a particular age group in their practices (e.g., pediatric, elementary, adolescent, adult, geriatric), accurate assessment must be conducted simultaneously by a range of professions. All human service professionals maintain an account specific to their field of how humans develop. Walsh et al. propose the biopsychosocial model in order to ground such accounts within an all-encompassing framework of development, thereby encouraging accurate, collaborative assessment.

The authors note that it has only been within the past decade that practitioners in a number of professions, including education, psychology, law, social work, nursing, and health, "have recognized the need for interprofessional collaboration in a wide range of training and practice settings." According to Walsh et al., limited data to support interprofessional collaboration is just beginning to emerge (Corrigan, 1996; Chalfant & Pysh, 1989; Dolan, 1995; Ellis, 1984; Fuchs & Fuchs, 1989; Golan & Williamson, 1994; Lawson & Briar-Lawson, 1997; Sindelar, Griffin, Smith, & Watanabe, 1992; Wang, Heartel, & Walberg, 1995). The authors suggest that positive findings are most evident in school settings via the implementation of integrated services. The Wang et al. study began with a literature search that identified 44 school-linked collaborative efforts having positive results. Data were then organized by category under six program areas and coded by outcome. With regard to the integrated services category, 95% of outcomes indicated "positive effects on students' achievement tests, grades, dropout rates, and attendance." The authors concur with Wang et al., however, that results of the literature search may be overinflated due to the likelihood that "only evaluations with positive results" were published.

Nevertheless, Walsh et al. assert that the "results of individual studies are worth reviewing." In the Golan and Williamson study of school-linked services in California, teachers were found to have benefitted from participation in the services through: 1) increased contact with parents and agency professionals, 2) greater feelings of helpfulness to students, and 3) further understanding of and appreciation for program services. Walsh et al. also review the work conducted by Chalfant & Pysh, 1989; Fuchs & Fuchs, 1989, and Sindelar et al., 1992, in which: 1) student-support and teacher-assistance teams improved student academic performance, 2) generated creative, appropriate interventions, 3) assisted teachers in mainstreaming students who were receiving pull-out services, and 4) "helped reduce the number of inappropriate referrals to special education."