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ABSTRACT

Children with serious emotional disorders receive inadequate and inappropriate services, rather than the comprehensive and coordinated system of care needed. To develop the knowledge needed to provide adequate and appropriate services, an alliance is needed among advocates, practitioners, and researchers. The Mental Health Services Program for Youth, supported by the Robert Wood Johnson Foundation, is a demonstration program intended to develop comprehensive and coordinated systems of mental health care. The community-level projects supported by the program develop such services as case management, emergency services, respite care, and therapeutic foster care. Each project incorporates a plan for integrating services and financial resources for children served by multiple agencies and service systems. A quasi-experimental design is being used to evaluate the program, by context, process, and outcome and by organizational, financial, and client characteristics. The evaluation design involves an interview-based organizational assessment, use of a management information system to assess client data, and a case conference involving input from all members of the clinical team. The importance of bridging the gap between theoretical and empirical knowledge to improve the current delivery system is stressed. (6 tables/figures) (JDD)

REFORMING MENTAL HEALTH SERVICES FOR SERIOUSLY EMOTIONALLY DISTURBED YOUTH:

RHETORIC, PRACTICE, AND RESEARCH[1]

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[1] Invited presentation in R. Hunter (Chair), symposium "Seriously Emotionally Disturbed Children: Policy, Prevention, and Treatment." Annual Meeting of the American Psychological Association, San Francisco, August 1991.

[2] This paper was prepared with the assistance of Gretchen Lovas, Theodore Cross and Judith Gardner, collaborators with the author on the Robert Wood Johnson Foundation (RWJF) MHSPY evaluation. Caroline Roan also assisted in the technical preparation of this manuscript. The work discussed in this presentation is supported by a grant from the Foundation to Brandeis University. Correspondence about this presentation may be sent to Leonard Saxe, Heller School, Brandeis University, Waltham, MA 02254 (e-mail: "saxe@brandeis")

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Several weeks ago, Rich Hunter (Symposium Chair) shared with me a draft of his introduction. The original draft included several quotes from a "state of the art" review of mental health services for children (Tuma, 1989) that appeared in the 1989 American Psychologist Special Issue on Children. I had an odd sense of deja vu as I read the quotes and I was prompted me to read the article carefully. To my surprise and chagrin, I discovered that much of the article (228 of 342 sentences) was taken verbatim, or with only minor editing, from a monograph I had written in 1986 with Ted Cross and several colleagues (Saxe, Cross, Silverman, with Batchelor, 1987) for the Congressional Office of Technology Assessment (OTA). The OTA monograph had been summarized in a public policy forum article for American Psychologist that had appeared only months before the Special Issue.

It is not my intent to digress from a focus on the important issues that face children with serious emotional disorders to deal with a purely adult problem. For the moment, I only want to provide a footnote for the record of what I discovered and, by doing so, share a private burden. It has been the occasion for much thought about the ideas that underlie what we advocate for children. In an ironic way, my discovery of this adult problem has relevance for what I would like to say this morning about children's mental health policy.

The thrust of our original monograph for OTA (and, by extension, the AP article) was that children with serious emotional disorders receive inadequate and inappropriate services and that we need to develop comprehensive and coordinated systems of care. These ideas are not necessarily original and have been the theme of several major national reports (e.g., President's Commission on Mental Health, 1978). NIMH -- through the Child and Adolescent Service System Program (CASSP) -- has been working to implement these ideas. Pending federal legislation (The Children's and Communities' Mental Health

Systems Improvement Act) will make them a visible feature of national policy. The view that our fragmented system of care for children needs to be rationalized and made comprehensive has become a fundamental tenet. Comprehensive and coordinated care have become the catch-words adopted by advocacy organizations from the APA to the National Mental Health Association. That the way of expressing these ideas would be adopted without attribution is, perhaps, only one indication of their widespread acceptance.

Unfortunately, between the rhetoric of advocates for a new system of children's mental health services and the reality of practitioners providing effective and efficient services, lie a number of unknowns. What is the actual magnitude of children's mental health problems? How is it possible that one out of five children has an emotional disorder that requires treatment? What do we really mean by comprehensive services? What are the limits to what society can and should do to assist troubled children and families? What types of interventions are most effective for what children? Are all Axis I diagnosed children equal in terms of their needs for services? What types of interactions are there between diagnoses and conditions such as poverty?

Until recently, mental health policy afficiandos -- in particular those interested in the welfare of children -- had to contend with a different dilemma. Existing knowledge about children's mental health problems and treatment was not being used (see Knitzer, 1982; Stroul & Friedman, 1986) -- even in a rudimentary way. We labeled this (Saxe, Cross, & Silverman, 1988) the "gap between what we know and what we do". But, the 1980s have given way to the 1990s. The 1990s are becoming the era of change for health and social services. One way or another, our health and social service institutions will be changed and children's mental health care will not be immune from change. The only question is who will influence what type of system emerges. If we want it to reflect the best that the science and practice of psychology can offer, it is essential to understand how to operationalize the concepts of advocates for children. Our urgent task is to develop a process whereby we can develop, test and implement new ideas about children's mental health care.

To implement new ideas is a great deal more demanding than developing consensus or gaining allies behind the right catch-words and phrases. Developing new systems involves translating principles into practice. The depth of our commitment to children and our individual skills as practitioners will be for naught unless we can develop the knowledge needed to provide adequate and appropriate services. To develop this knowledge base, an alliance is needed among advocates, practitioners, and researchers. It will, undoubtedly, be an alliance fraught with tension, but hopefully a healthy tension.

The tension is a result of differences in perspective. Advocates need to see problems in simple ways and upbraid those who diminish the needs of children. Practitioners must exude confidence about their interventions and avoid the burden of skepticism about the efficacy of care. Researchers must maintain a skeptical frame of reference and view all ideas as tentative hypotheses whose acceptance is merely a confirmation rather than a proof. Nevertheless, for ideas to get to the stage where practitioners can innovate with them and new knowledge be developed, collaboration is required. If we are to improve the chaotic state of care for children with emotional disorders, there is really no alternative to our joining forces. Today, I would like to describe one effort of advocates, practitioners and researchers to join together to develop new models of care for children with serious emotional problems. My father used to tell me "Wait 'till you get older and learn how much you need to learn". I hope from my discussion today it will be clear that we have much to learn about children's mental health care, but that we have finally launched some important efforts to reform a dysfunctional system.

Robert Wood Johnson Foundation Demonstration

Much has changed in the 5 years since I worked on our report for Congress on the state of children's mental health care, but it is clear that the fundamental problems of lack of access and appropriate care have not been solved. Some children are probably receiving more appropriate care, and the growth of psychiatric hospitals has been restrained (perhaps by reducing the average length of stay), but it is not clear that we have made the fundamental changes necessary to provide appropriate universal care. In a recessionary economic period where federal, state, and local governments play a game of "hot potato" over responsibility for health care and social services, it may be delusionary to believe that much could be accomplished.

One exciting development, however, is a series of demonstration projects now being conducted to test new ways to provide services. Demonstrations are being carried out by several states, as well as by the Department of Defense. One of these demonstrations, the Mental Health Services Program for Youth (MHSPY), is supported by the Robert Wood Johnson Foundation (RWJF). The Foundation wants to demonstrate that services for children and youth with serious mental illness can be improved through comprehensive and coordinated systems (Beachler, 1990). RWJF is providing approximately $2.5 million to each of 8 states over the next 4 years to aid them in improving the system of care for seriously emotionally disturbed children. States will use Foundation funds to supplement existing resources and will make structural changes in the organization and financing of mental health services. As part of this demonstration, we are conducting an independent evaluation of the initiative.

Goals

The RWJF demonstration is intended to support model systems of care in geographically and socio-economically disparate communities (Figure 1). It is a project that resulted from the work of advocates for children, was designed by practice experts, and includes a research component. The project probably fails to meet fully the needs of each these groups -- the funding is not large enough to make a substantial difference, practitioners have little flexibility, and as a research effort the potential for unambiguous assessment of hypotheses is limited. Nevertheless, it is a model of collaboration and a prototype of how ideas about improving care for children with serious emotional disorders can be implemented and tested in actual settings.

The RWJF initiative is designed to encourage state and local community innovation. States are the recipients of RWJF funding, but the projects are being carried out at the community level (depending on the site, the operating agency may be a unit either of state or county government). The component services of the RWJF projects are varied (See Table 1). They range from case management and emergency services (features of all projects) to day treatment and therapeutic foster care (explicit features of most projects) to respite care and transition services for adolescents (present in only some projects). Each project also incorporates a plan for integrating services and financial resources for children served by multiple agencies and service systems. And each project proposes to restructure how services are financed. Funding is perhaps the glue that ties all of us concerned with mental health for children together.

My goal, as evaluator, is to provide objective, usable information about the demonstration -- for the projects and Foundation, but ultimately for the wider audience of those who make decisions about mental health policy. The raison d'etre of the research study is to provide information that will facilitate replication of effective programs. Although the logic of such research is no different than that of any type of research, we have a special obligation to identify the contextual factors that underlie program effectiveness. Historian of psychology E. G. Boring remarked once that "today's confound becomes tomorrow's independent variable". The evaluation task is to understand the confounds that interfere with the effectiveness of theoretically effective care for children with mental health problems.

The key construct being tested by the demonstration is that provision of comprehensive and coordinated mental health care is more effective and efficient than more fragmented systems of care for seriously emotionally disturbed children. "Comprehensive care" has been operationalized by the projects as the implementation of a "continuum of care" that encompasses a broad range of services. "Coordinated care" is operationalized by the provision of case management services and implementation of joint or interagency structures and working agreements. Each site is implementing these constructs somewhat differently; improvement in the quality of care is anticipated as an outcome of a more comprehensive, coordinated service system.

Although the projects supported by the RWJF initiative share a common conceptual base, states and communities differ substantially in their governmental structures, in their financial operations, and even in the problems faced by their children. Thus, we need to collect a considerable amount of idiosyncratic data about each site and be as descriptive as possible. Our primary task is to identify the components of comprehensive, coordinated child mental health systems and their relationship to service provision and costs. Second, we need to understand the impact of systems changes on children and their families.

Methodology

Knowing what we need to understand and developing appropriate methods are somewhat different problems. For the researcher, this is the equivalent issue to translating ideas about mental health care into actual treatment interventions. Unfortunately, available tools to assess mental health systems are derived from clinical research and the assessment of individual change in psychopathology. The RWJF demonstration requires that we collect information at a different level and that we integrate clinical data with organizational data.

To guide the research, we have identified a series of research questions (see Table 2). The questions are organized by context, process, and outcome and by three "domains of inquiry" -- organizational, financial, and client. We need to understand the nature of the systems, the resources available, and the clients. Eventually, we need to link answers to these questions to outcomes, hopefully, through understanding the mediating variables (process questions). It is undoubtedly a complex way of thinking about the project, but providing comprehensive and coordinated care is inherently complicated.

The evaluation design is quasi-experimental, with comparisons among the sites and, in some cases, to non-project sites as the essential approach. But, the far more difficult problem, given the nature of the demonstration, is how to measure the dependent variables. Our decision is to use multiple methodological strategies; in essence, to collect data from a number of different perspectives. Currently, this involves: (a) An interview-based organizational assessment; (b) use of a management information system to assess client data; and (c) a case conference involving input from all members of the clinical team.

Organizational assessment. The first design component uses structured interviews and document review to collect data to describe the organizational and financial systems at each site. In-depth case studies of each of the eight projects fully funded by RWJF and more limited case studies of the four sites that received only initial implementation funds will be developed. Each case study has several goals (see Table 3): (1) to describe the environment for children's mental health services, (2) to document the structure of the service system, (3) to describe the nature of interventions to be supported by each project, (4) to document the sources of funding for the range of services, (5) to describe the specific client population, and (6) to chronicle the changes in coordination, provision and funding of services that are the result of project implementation.

Management information system. One of our innovative efforts to collect usable data consistent with the needs of the system is to take advantage of the information collected routinely as part of project management and accountability. Although each state (and, in some cases, each agency) maintains different record-keeping systems, they all collect extensive client-based data on clinical encounters and finances. In collaboration with the MHSPY National Program Office (Drs. Cole and England), we are developing a sophisticated computer-based system for such record-keeping.

The Management Information System is called SEDTRACK, with a short version dubbed QUICKTRACK on the way (see Table 4). When fully implemented, it will allow a case manager to enter information about a child and family into a PC. SEDTRACK will give case managers a powerful relational database program to organize the disparate information about children and families being served and make it possible to update easily records and case plans. There is nothing simple about this program, but the idea is that managing complex cases is hindered by manual record keeping systems and is actively frustrated by inflexible linear record keeping systems.

From a research perspective, the advantage of SED/QUICKTRACK is that all of the information about clients and families will be available for analysis, without duplicative assessment and coding. We have developed a common data protocol (information being collected on all clients) at each site. The goal of the system is to enable us to describe the clients and the services they receive. Information in the system will include both client-specific clinical information (e.g., history, functional status, family information) and information about the provision of services. System components and their utilization status within the system will be derived from these data, along with financial data about the system.

The data system will provide information to answer several important questions about the demonstration. Costs of services can be inferred by obtaining data from local providers on average costs for services. The system will also yield counts of "use" of each of the involved systems and will supplement more qualitative information collected by interviews. The system will enable verification of the involvement of multiple agencies in service provision and will identify the characteristics of the treatment team. Data from the system will enable us to compile reports describing and comparing the sites. Examining client records for all of the children at a given site, will also enable us to determine characteristics of the children being served: ages, diagnoses, family constellation, history of involvement with different systems.

Case conferences. One of the most difficult problems is how to evaluate clinical outcome in the context of a systems change effort. That scores on a measure of psychopathology change or do not change is not a very sensitive measure to assess the quality of care to chronically disturbed children. Seriously disturbed children may appear quite dysfunctional even when appropriate treatment has been provided; as well, while a child's symptoms may be greatly reduced, for example, in response to intensive intervention, the level of symptomatology at one point says little about the child's eventual adaptation to the community. Moreover, psychopathology measures fail to identify the link between provision of services and change. Although randomized clinical trial designs might allow inferences about these matters, they are particularly problematic when used in quasi-experimental research such as the present study.

As an alternative, we are developing (in collaboration with the Yale University Child Study Center) a procedure to conduct and analyze case conferences on a sample of clients served by each project (see Table 5). Our goal is to develop a "picture" of how the systems implemented by each of the project sites work in practice. Our method involves gathering all of the members of the service team for a particular child and asking them to review systematically the diagnostic evaluation, the interventions and the outcomes of intervention. The procedure is designed to capture a rich portrait of the children treated by the project and understand the process by which providers decided upon specific interventions.

These case conferences will include the presentation of a capsule version of a traditional case history as well as a consideration of the completeness of treatment providers' evaluation of the child (e.g., "Was the treatment sensitive to issues of race, ethnicity and social class?", or "Does the diagnosis adequately describe the problem?"). Clinical team members will be asked to assess the treatment process as well, considering what treatments at which "doses" children received and what treatments may have been preferred but were not available. Patterns of service utilization and associated costs and their relationship to clients' needs will be examined longitudinally. The resulting data will also be used to understand the ways in which organizational and financial structures, policies and regulations enable or impede the provision of those services in individual cases.

Conclusions

Researchers are adept at identifying problems and describing theoretical solutions. We are, however, perhaps constitutionally incapable of helping practitioners solve specific problems. I will not disappoint those of you who share this view of researchers by offering much in the way of concrete advice. I would, nevertheless, like to make some specific observations about what we know and do not know about mental health services for children. It is too early to tell you much about what we have learned directly from the RWJF demonstration, but my experience developing this research has helped me clarify the essential questions.

- Perhaps, most importantly, we already know that treatment is better than no treatment. With confidence one can reject the null hypothesis and say that it is better for an emotionally disturbed child to receive professional mental health interventions than not. Substantial evidence demonstrates that interventions do help children and that children, even with serious problems, can be helped. We do not, however, know for which children and under what conditions treatment is most beneficial.
- We also know that inappropriate treatment (e.g., too restrictive, lacking

in intensity) is bad. Some children do not need to be in hospitals. Other children with serious disorders, left in dysfunctional environments without a supportive adult, need to be in some form of residential care. We do not, however, yet have a well-tested protocol for determining the appropriateness of an environment for a child.

- We also know that fragmented treatment -- where, for example, treatment provided in a residential setting is not followed by aftercare, is poor. But, we do not know how integrated treatment has to be. Should, in fact, there be a single treatment team and is it poor treatment, by definition, when the same person who provides therapeutic interventions is also responsible for decisions about the length and site of treatment.

With each of these issues, how we choose to answer the question is crucial. No longer can we be concerned with purely clinical outcomes (i.e., impact on psychopathology), but we must be concerned with resources and resource use. Long-term psychotherapy may be effective, but may be far less cost-effective than other types of interventions. The problem becomes even more complex when one knows that treatment is inappropriate, or is less effective than an alternative, but the treatment being offered is the best that one can offer. Better to have a child who is out of control in a locked residential setting than not getting any treatment. Better to see the child once a week, than not at all.

To fix the current system we need to bridge the gap between theoretical and empirical knowledge. We need, for example, to know how to operationalize coordination and be able to predict the effects of case management. We need to provide guidance on what kinds of systems of care will be effective and how care can be delivered efficiently. In sum, we need to use both our clinical wisdom and research skepticism if we are to play a role in restructuring mental health care for children and for making critical decisions about allocating resources.

I am convinced that reform of mental health services for children can proceed only if there is a strong alliance among advocates, practitioners, and researchers. Advocates need to goad those who control resources to develop new programs and end our society's shameful neglect of children. Practitioners need to consider new ways of providing services and work with advocates to insure that innovation is the hallmark of children's mental health care. Researchers need to collaborate with both of these groups to insure that we can learn from innovations in care. We can go from rhetoric about the need for better services to a more effective system, but it will require more than the resources generated by advocacy and the good will and efforts of mental health professionals.

New knowledge is critical to this enterprise. There is no shame in our admitting that while we know the general direction that innovation must take, our specific ideas are tentative. As a researcher, I know all too well why the collaboration that I view as essential has not worked and why conflict has replaced creative tension. Too often, researchers have attempted to impose methods that are not appropriate to the questions, while practitioners have been unwilling to view what they do as testable. At least in the case of children with serious emotional disorders, we need both innovation and research to help us develop a system that serves children, their families, and society.

Each of us separately -- advocates, professionals and researchers -- has now gotten the attention of policy makers. For researchers, the adoption by NIMH of the National Plan for Research on Child and Adolescent Disorders is a palpable sign that our work is recognized as critical. I hope that the re-creation of NIMH as an NIH Institute, and the divorce of its service programs (to be adopted by a new "family" with the acronym ADAMHSA) does not symbolize the termination of government-sponsored collaboration between those who do and those who study what others do. There really is no alternative.

A final comment about the role of psychology. As we develop a new system of care, psychologists have a particularly important role to play. Multiple players are jockeying for dominance in dealing with children mental health -- psychiatrists, economists, policy experts, and even lawyers. As a profession with our "feet" (if not our heads) firmly planted in both science and practice, it is imperative that we play a central role. For the sake of our children, and the families who struggle with the most difficult problems of life, I hope none of you is dissuaded by the complexity of the problem.

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FIGURE 1. MHSPY DEMONSTRATION SITES

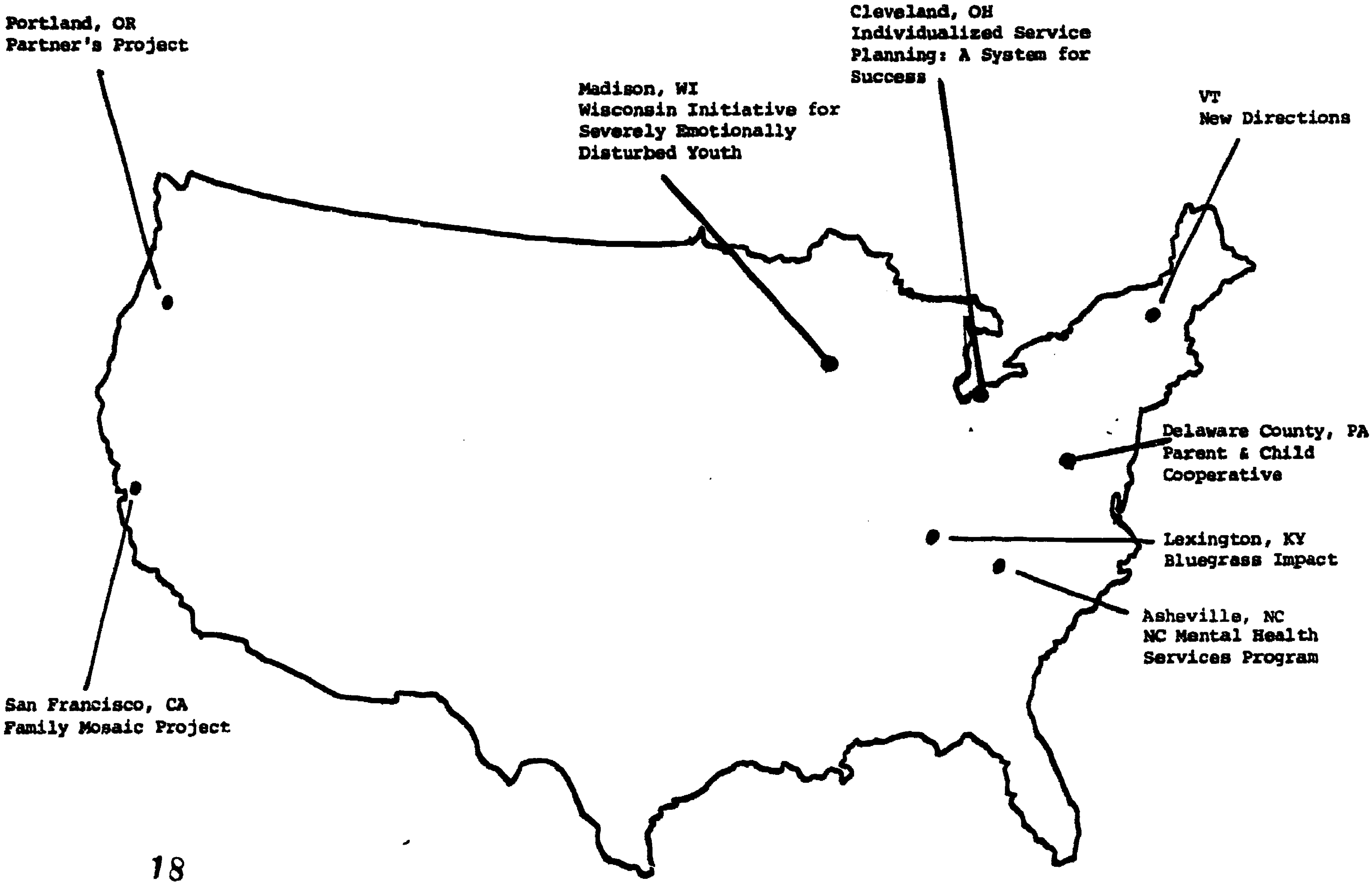

TABLE 1. RANGE OF SELECTED SERVICES AT REPRESENTATIVE MHSPY DEMONSTRATION SITES

SERVICE	Ohio	Pennsylvania	Vermont	Wisconsin
Outpatient therapy	O	O	O	O
Emergency stabilization	O	O	O	O
Crisis outreach	O	X	X	X
Interagency case management (> 1:15)	O			
Intensive case management (≤ 1:15)		O	X	O
Respite care		O	O	
Intensive home-based services	O	O	O	O
Therapeutic foster care	O	X	O	O
Transitional living programs	X	O	O	O
Group residential care	O	O	O	O
Intensive residential treatment	O	O	O	O
Hospitalization	O	O	O	O
Day treatment	O	O	O	O
Wrap-around services	X	O	O	X
Parent support network		O	X	

O - In place at beginning of MHSPY project.
X - Being put in place as part of MHSPY project.

TABLE 2. MHSPY EVALUATION RESEARCH QUESTIONS

	ORGANIZATIONS	FINANCES	CLIENTS
CONTEXT	Socio-demographic features Prior history of change Components of system Interagency structures Services available	Public and private resources Legislation and regulations Other factors which restrict: - service provision - financing of services	Socio-demographic profile Functional characteristics Profile of treatment history Profile of service system use
PROCESS	Interagency relationships Coordination of services Role of case managers	Coordination of resources Blending of resources Resource allocation	Services used Services not available Service/need match
OUTCOME	Changes in system Changes in coordination Impact of case management	Changes in financing Cost of services High-/low-cost case profiles	Changes in adequacy of care Changes in functional abilities

TABLE 3. ORGANIZATIONAL ASSESSMENT

From: Interviews, Surveys, Document Review	Sample: Direct Service Providers, Administrators, Parents

Change Plans

History and context of change effort

Strategies for managing and implementing change

Organizations

Components of the service system

Interagency structures, mechanisms and relationships

Range and capacity of available and proposed services

Coordination of services

Case management and it's relationship to other service provision

Finances

Funding stream shifts and reallocations

New resources to be added to system of care

Clients

Socio-demographic characteristics of general population

Definition of the target population

Points of entry to the service system

TABLE 4. MANAGEMENT INFORMATION SYSTEM

From: SEDTRACK/QUICKTRACK Sample: All MHSPY Clients

Referral

- Socio-demographic information
- Clinical status and history
- Relevant medical, educational, social service, juvenile justice status and history
- Relevant status and history of family members

Plan of Care

- Issues and goals
- Services needed
- Assignment of financial and service provision responsibility

Treatment

- Significant events
- Changes in Plan of Care
- Services received
- Organizational components providing services
- Units of service received
- Cost per unit of service received

TABLE 5. CASE CONFERENCE

From: Clinical Case Conferences   Sample: Sample of MHSPY Clients

Availability and organization of resources at conference

Difficulties/needs of child

Strengths and weaknesses of adult care givers and organizations

Optimization of clinical care

- Treatment alliances
- Coordination of services
- Flexibility of services/treatment planning
- Availability of resources
- Adequacy of monitoring
- Adequacy of care
- Adequacy of planning
- Process of consensus within conference

Adequacy of treatment team's work