Developing a Community-Based Care System for Seriously Emotionally Disabled Children and Youth

By: Cathryne L. Schmitz, MSW and Lewayne D. Gilchrist, PhD

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Abstract:
The needs of emotionally disabled children and their families are not optimally served within traditional mental health service delivery systems. Policies are inadequate, delivery systems are insufficient and underfunded, and supporting research is sparse. As communities begin addressing the needs of the seriously emotionally disabled child and family, planning should address community coordinated services. Such systems, however, are not easily established and maintained in communities accustomed to addressing children's needs in terms of existing fragmented categorical structures. National models exist but care and time are required to adapt critical elements from these models to local need. This article will review the rationale for integrated community-based, case management services for children and adolescents. A case example is offered illustrating issues affecting the development of one community support system.

Article:
Understanding and responding to children's mental health problems is difficult for a number of reasons. Not the least among them is the interaction between the child's individual psychopathology and environmental factors that aggravate or precipitate his/her emotional difficulties. Children are uniquely dependent on their environment and strongly affected by stresses present in their families. Therefore, treatment involving all support structures—family, school, and community—as well as the individual child is imperative (Saxe, Cross, & Silverman, 1988; Tuma, 1989). When children suffer from emotional difficulties, a broad range of areas including intellectual, developmental, behavioral, emotional, and physical development are affected. Children are impacted behaviorally and emotionally by such factors as maltreatment, sexual abuse, neglect, and parental psycho-pathology (Watt, Anthony, Wynne, & Rolfe, 1984). Environmental factors such as poverty are also related to psychosocial stress and higher rates of mental disorders (Albee, 1986; Gould, Wunsch-Hitzig, & Dohrenwend, 1981; Institute of Medicine, 1989; Tuma, 1989).

The issue is further compounded by the difficulty encountered in attempting to define the population to be served. In 1982 Jane Knitzer pointed out the inadequacy of attempts to define the population. Labels like mentally ill, behaviorally disordered, and psychotic are too narrow to address the range of issues. For this article the children and youth needing services are referred to as seriously emotionally disabled. The definition, however, is still problematic. The definition must be narrow enough to reflect only those children and youth with severe emotional problems. It must, however, be broad enough to allow the inclusion of children and youth impacted by a broad range of emotional, behavioral, and environmental conditions affecting their emotional and mental health development in diverse ways. These children may be in any one of the many child serving systems—child welfare, special education, mental health, juvenile justice—and there-fore be defined in a variety of ways (Institute of Medicine, 1989). According to Stroul & Friedman (1986).

> The target population should include children whose emotional problems are disabling based upon social functioning criteria. Level of functioning is a critical variable for children and adolescents, determining the nature and level of care that is appropriate. Degree of disability or level of functioning

> in family, school and community contexts is often more meaningful than mental health diagnosis in planning and delivering services. (p. 7)

Defining the group too narrowly will result in the exclusion of children and youth desperately needing services. A definition which is too broad, however, offers few guidelines for agencies and systems struggling to make difficult decisions with limited resources. Because severely emotionally disabled (SED) children require involvement by multiple agencies, SED children in the Seattle project were defined as those children and youth with mental or emotional disturbances of one or more years requiring the response of two or more systems. Service delivery is also complicated by both the range of factors impacting children and system regulations/barriers. Mental health professionals need to provide a broad range of services cutting across a variety of systems. The current structure of health care financing and the lack of coordination among existing agencies serving children, however, has a significant negative impact on the delivery of mental health services to children (Saxe et al., 1988). Although systems are attempting to redirect funding to community services, the majority of the funding available for children's mental health services is still focused on fairly restrictive and costly residential treatment and psychiatric inpatient facilities (Stroul & Friedman, 1986; Saxe et al., 1988). While these services are less cost effective than community services and isolate the child from his/her natural environment, historically most of the treatment and research dollars have been focused here. Non-institutional, community-based services provide the potential for more beneficial, cost effective treatment. Community treatment allows treatment which involves the community and impacts environmental conditions affecting children's mental health. Serving children in or as close as possible to their own communities maximizes the possibility of family involvement and allows for reintegrating the child into the natural environment (Behar, 1984). There is, however, a severe lack of the community-based, case management services needed to provide the coordination and support necessary for community treatment (Dougherty, Saxe, Cross, & Silverman, 1987).

National Models of Community-Based Services for Children

The inadequacy of children's mental health services in meeting the needs of SED children has been studied and documented repeatedly (Joint Commission on Mental Health of Children, 1969; President's Commission on Mental Health Services, 1978; Knitzer, 1982). However, little work yet exists which empirically explores new service options for children. Recently, a few publicly funded projects have been undertaken to explore the feasibility of community-based services for emotionally disturbed children. As the result of a lawsuit, North Carolina developed one of the first, community-based systems of care providing a full continuum of services. The new system significantly reduced the number of children and adolescents that were sent out of the region to be housed in secure settings (Behar, 1985). The concept of individualized care developed in North Carolina was carried forward in the development of the Alaska Youth Initiative (AYI) and the Ventura County Project (Alternatives to, 1988). Case management has been at the hub of each of these exploratory new directions in brokering services and increasing effectiveness (Individualizing Services, 1988).

Case management at least in theory has several advantages in treating psychiatrically disabled children. As recent exploratory studies show, however, case management services cannot exist outside of a broader, community-wide structure that supports them. The next sections expand on case management as a viable direction for children's services and on the broader system management issues.

Role of Case Management

To develop comprehensive services, a mechanism for implementing treatment which coordinates the child's multi-faceted environment must be developed. Case management, as a co-ordinating mechanism, can ensure appropriate and responsive treatment decisions while monitoring service delivery (Behar, 1985; Stroul & Friedman, 1986). A case manager unifies service delivery (Behar, 1984) by orchestrating the coordination of services, and attempting to ensure flexibility and responsiveness while keeping the system together (Case Management, 1986). Both advocating for clients (Knitzer, 1985) and brokering services (Stroul & Friedman, 1986) are important and necessary roles for the case manager. For effective community-based services, agencies and systems, including mental health, social services, juvenile justice, and education, must work together in close cooperation.

Case management ensures that: a) numerous key components are coordinated, b) the delivery of these services is assessed over time, and c) appropriate services are modified as the child's developmental level shifts and the needs of the child and family change (Stroul & Friedman, 1986). The continual monitoring and treatment plan updating required to address children's ongoing developmental change can be neglected in more traditional or categorical service systems because of the lack of coordination. The goal of case management is protection of the rights and needs of the child and family. The Ventura County Project (1986) is an example of an effective comprehensive system where the case manager is responsible for assessment, planning, linkage, monitoring, and advocacy.

Management of the System of Care

Because the building of comprehensive, community-based systems responsive to client need is new, little attention has been paid to the issue of the management of the system (Stroul & Friedman, 1986). According to Isaacs' analysis (cited in Stroul & Friedman), "the development of well-conceived, viable, and continuing networks demands long periods of time and high levels of individual and agency commitment" (p. 120). Nationally, there appear to be three major approaches taken. to the development of model community support systems that are based on case management. These include: 1) management by a central system, 2) management by a lead agency, and 3) management by a committee developed from multiple agencies (Stroul & Friedman).

Theoretically, management of coordinated and comprehensive services by a central system (a consolidated children's department) can solve many of the issues related to barriers between systems. If the system is organized in a way which facilitates cooperation, this approach can lead to a team investment in service availability. Connecticut, Delaware, and Rhode Island have a state level consolidated children's services agency. Even in states with the most consolidated services, however, education and recreation are frequently separated. Quasi-consolidated models exist in Florida and New Hampshire with some division at the state level. Consolidation makes the task of coordination easier because one or two agencies generally provides the services and/or funding for children (Stroul & Friedman, 1986).

Ohio serves as an example of a system managed by multiple departments (Stroul & Friedman, 1986). A cluster, formed with representatives from all child-serving agencies, meets regularly at both the state and county levels to review cases and develop plans. Clear roles and responsibilities and strong leadership as well as joint funding are required within a system managed by multiple departments. Management by this model requires careful planning, good problem solving mechanisms, and mutual respect (Stroul & Friedman). The use of the cluster model may result in extreme local variability with only nominal commitment by the agencies and systems involved unless strong leadership is provided.

When service co-ordination and management is provided by a lead service agency rather than a central system, agreements must be worked out between agencies and systems. A willingness to cooperated combined with a clarity about roles and responsibilities is necessary. North Carolina developed the Willie M. Project providing the full range of services for the most disturbed children and youth based on the lead agency model (Behar, 1985). Without strong state and local leadership, this model can result in extreme local variability as well as competition rather than coordination and cooperation. A com- munity support system located within a community operating under the lead agency model developed in Seattle, Washington. The Seattle community support system involving intensive case management as a core service is reviewed as one example. The framework presented can be an appropriate starting point for communities building a community support system especially if the system is based on the lead agency model.

Development of a Community Support Service

The development of a community support system is a lengthy, time consuming, and ongoing process intertwined with the development of an interagency community network. The combination of shared goals, time, and strong leadership are necessary for building a collaborative community system (Knitzer & Ye1ton, 1989). These conditions came together in King County, Washington. Seattle Mental Health Institute (SMHI) was a part of this process. Key members of the agency invested several years into the community work

necessary for the building of an interagency community network. This community net-work offered the potential to support a community support project. Prior to the development of a community support model, SMHI actively involved itself with other agencies and systems in the process of building the interagency community team in a community and state investigating national models for integrated community-based services. The development and implementation of SMHI's community support program for children provides an example of how one community developed its initial community support program. The presentation focuses on the actual preparation and implementation phases as they worked in this instance. Comments about subsequent development are provided and suggestions are offered for the third or evaluation phase.

Like most models, SMHI's system has both strengths and weaknesses. It is a small system located within one agency in a state struggling to implement community care systems. As a model program, it had to be developed with limited knowledge and significant risk. As a result, staff faced significant periods of role confusion and transition. The project started with a team of four case managers (including the supervisor/team leader) providing in home support 24 hour a day seven days a week. Although the start up was difficult for the staff, new projects would never be implemented if communities waited until the perfect time.

Preparation Phase

In the spring of 1986, the child serving agencies and systems in King County, Washington and the University of Washington came together to build an intersystem/interagency network called the Children's Mental Health Health Advocacy Group (CMHAG) to examine the need for coordinated community services for children and youth. Strong leadership and a common goal—improving services for emotionally disabled children and youth—provided the focus. The specific goals of CMHAG included increasing collaboration, assessment of service gaps, and advocating for movement toward a full continuum of care. A cohesiveness developed within the group over the first couple of years based on the goals and an ongoing time commitment by group members.

Without the collaborative work of CMHAG and the cooperative relationships evolving from the group, the CCSP at SMHI would not have been possible. Because of the intersystem collaborative nature of the group, the trust necessary for coordinating community-based services developed across systems. Building on relationships formed through CMHAG, staff from SMHI worked closely with key staff from the Division of Child and Family Services (DCFS), local and regional educational personnel, members of the juvenile justice system, the local mental health authority, and other child serving systems in developing the close cooperative working relationships that became necessary in the next phases of development and implementation.

Concurrently, the community, including SMHI, began to study national case management and community support programs by examining. key elements and commonalities. Based on that work, several key elements were determined to be vital to a successful community support project. These included: a) comprehensive individualized service for the child or youth and family; b) home and school based service availability; c) the ability to assure the supports needed in existing systems, especially education; d) a full range of support and educational services; e) low caseloads; and f) 24 hour response capability. With these key elements in mind, a thorough assessment of the local community indicated that many of the service elements were not available. Therefore, it was determined that a community support service would need to provide and/or advocate for the development of many service elements. While a local network is vital to the development of any community support service, it was especially important in Washington State because neither a consolidated children's agency nor a multi-agency management team exists at the State level.

Implementation Phase

In late 1987 SMHI had developed formal plans for the Children's Community Support Project (CCSP). These plans were ready to be presented in response to a request for proposal for a children's com-munity support service from the local county mental health authority. The application was funded in early 1988 with an ongoing commitment of state mental health funds. To get CCSP up and running, SMHI personnel developed working agreements with 17 agencies and systems including DCFS, education, inpatient and outpatient mental health providers, residential services, and other child serving systems. These working agreements included a

precise definition of the population to be served.

As with the adult community support movement, increasingly limited resources within the children's system has led to the development of community support services for the multi-system, multi-problem child. Consistent with this thought, Seattle's system was designed to serve only the most disturbed children and youth. The need to limit the population served led to definitional difficulties. In an attempt to limit access to the most disturbed, children and youth served by CCSP were initially those either being released from inpatient psychiatric hospitals or mental health residential facilities, or on the waiting list to enter such facilities. It became clear, however, that the project was missing a significant number of children and youth it was designed to serve. Therefore, the eligibility criteria were revised, expanded, and shifted to include children and youth at risk for placement in more restrictive settings. The admission process was later revised to include review by a subgroup of CMHAG. The new entry system was designed to bring systems together to form a collaborative plan for highly disturbed children and youth experiencing difficulties in at least two service system sectors (education, mental health, home, DCFS, and/or juvenile justice). This new process further integrated the team into the ongoing networking and incorporated some elements of management by a team. The process and definition continue to be revised to meet the need for serving children and youth with severe problems.

In putting the project into place, difficulties were encountered. During the first year of operation, the primary difficulties encountered were inappropriate staffing decisions, car insurance and liability, underfunding, unanticipated high demands on staff time and energy, role confusion, and regulatory and policy barriers. Initial lack of clarity about the type of caseload, size of caseload, and case manager involvement in direct service increased role confusion and stress. As a result, staff hired needed to be not only competent, but also well educated and trained, respectful of families, able to tolerate ambiguity, flexible in providing services and meeting the needs of the child and family, independent in their work, and able to work effectively given the lack of resources. The psychiatric consultant must also be flexible both in openness to alternative forms of treatment and in willingness to meet clients outside the office.

Role confusion and lack of clarity about functions and tasks led to a turnover rate of 30% during the first year of operation. Strong, consistent supervision, team support, and agency/team cohesiveness are required to deal with these dilemmas. Housing staff together in one large office helped increase cohesiveness when combined with strong, positive supervision. The first community support project in a community faces particular difficulty because there are no experienced providers to offer assistance. While input from model programs is useful, it must be modified to meet the specific needs of the community since communities differ in service/resource availability, regulatory/ policy barriers, political alliances, historical perspective, organizational/system structure, and openness to new ideas/change.

Established systems resist changes that include new potential liabilities. Insurance companies are hesitant to include new dimensions such as covering staff driving children with emotional problems in cars. Initially, regulatory and policy barriers may increase rather than decrease as new issues arise. Persistence, creativity, and both administrative and system support are required to overcome these barriers.

CCSP with the backing of the interagency network, CMHAG, has been successful in coordinating many of the services needed by the children, adolescents, and families. The child serving agencies and systems have been cooperative and helpful but difficulties related to funding barriers and lack of a strong overall system are still encountered. Because there is no state level structure coordinating systems such as education, child welfare, and mental health, regulations about service provision and funding requirements prohibit cost efficient, coordinated services in many instances. Regulatory impediments limiting access to services in combination with an actual short-age of service options—such as respite care, home back-up services, and therapeutic foster care—have created difficulties requiring intensive case management to fill in the gaps and maintain community placement. This added requirement has increased both the stress and role confusion experienced by the case managers. Initial case reviews indicate the program has had some success in providing increased community tenure and more coordinated supports for the families served. The intensive needs combined with the lack of

service backup, however, requires caseloads as low as 5 to 8 children or youth per case manager.

The project's first year of operation facilitated increasingly tangible commitment on the part of DCFS, education, mental health, and juvenile justice to coordinate services. The systems are committed to working toward the development of mental health service systems, educational systems, and home support systems that are more responsive to the needs of SED children and their families. SMHI continues to work with the county mental health authority as well as Child and Family Services on a small project to try in-home support and respite care so children can remain in the community during periods of crisis. Development of more intense support in the schools and/or collaborative day treatment services that are appropriate to the needs of the most disturbed children and adolescents are necessary over the next several years to fill in major gaps in the system. Many families have responded positively to the program and want to maintain the children/adolescents at home. Future planning will need to encompass back-up and support services for families experiencing crisis periods.

The proper organizational climate and structure are required to get a children's community support service off the ground. Once the structure and specific program components are in place, the problems and barriers become apparent requiring adjustments at both the agency and system levels. The third year of the project, after stabilization, has seen expansion into services for homeless youth, intensified crisis services, and more focus on support for specialized community placements. After these initial implementation steps occur, planning can then turn to implementing a good evaluation.

Next Steps in Development

Although resources are limited and initial planning legitimately focuses on service delivery, formal project evaluation must occur. Without evaluation and research beyond the ongoing clinical assessment needs, knowledge about the vital elements will remain limited. Monitoring and evaluation can provide knowledge about why a program is working or how to replicate it (Brekke, 1987). Evaluation activities, however, should not be launched until the program has stabilized into a smoothly operating, predictable operation (Weiss & Jacobs, 1988). Once the structure and specific program components are in place, the process of evaluation can move forward.

Gaining consensus on the key variables that constitute program success is difficult and sufficient time should be allowed by program planners for this task. This is particularly important when outside consultants are called in to assist in the evaluation process. Some knowledge can be gained by examining research on adult models and carefully tailoring elements of these studies to fit the current need. Client outcome data can also provide some initial speculation as to key variables.

While much has been studied in relation to community support services for adults, little has been done to study the range of community support services needed for children and adolescents to succeed in community-based services. Numerous studies validate the effectiveness of case management systems with adults (Intagliata & Baker, 1983; Rapp & Chamberlain, 1985; Stein & Test, 1980). Based on their examination of data available from studies of case management with adults who have chronic mental health problems, Intagliata & Baker identify key factors affecting the functioning of case managers as a system integration mechanism. According to the data, case managers with higher levels of education are better able to handle the high levels of autonomy and independence required by the case management position but also face higher levels of burn out. Other factors of significance include: a) low caseloads; b) clarity of expectations; c) consistent, frequent supervision; and d) support from other parts of the system. It has been well established that case managers cannot adequately perform their duties without interagency cooperation and a sufficient service network (Baker & Weiss, 1984; Schwartz, Goldman, & Churgin, 1982). Adult data has been useful in providing direction as programs develop. The data are also useful in identifying some key components for evaluation, and consistent with the experience of the Seattle children's project. Care should be taken, however, not to assume that adult models are adequate for or responsive to the range of needs experienced by children and their families.

Quantitative and qualitative research can be used in a complementary fashion (Hopps, 1990). Qualitative

research could be valuable in the initial stage of research to identify the key components from the perspectives of the children or adolescents, families, case managers, and community at large. More quantitative research could then follow examining the key relationships identified. The use of multiple methods can help overcome the deficiencies and biases of any one method (Mitchell, 1986). Because it is very difficult to limit measurement to those few variables that can reliably be collected by staff without overburdening them, relationships with local colleges and universities are necessary if adequate evaluation and research are going to occur.

Discussion and Recommendations

The service needs of the most disturbed children and youth are complex and multidimensional. These needs are best met in the child's local community where environmental as well as individual factors can be dealt with. Unfortunately most of our resources continue to go into institutional care leaving us with little usable knowledge about how best to serve disturbed children and adolescents in the local community.

Several national models currently exist that local communities can study and learn from. Translating these models into viable working relationships and lasting program components, however, is an extremely time consuming and complex process. Each community must assess it's own resources and deploy those resources in unique, individualized ways. Interagency networks are vital to the development of community based service. Through these networks a power base can develop over time which will serve as a base for child advocacy and program development.

The initial Seattle/King County project provides a model for the development of a community-based care system provided by a lead agency within a community which has an active multi-agency group with a working history. Without this history, the project could not have been initially developed. The approach to case management/ community support used requires careful planning, as well as mutual respect among the agencies and systems. Over the years, mechanisms for solving the difficulties that arise between systems have been worked out. To develop coordinated services for successful intervention with seriously emotionally disabled children and adolescents, common philosophies and values must develop and the financial and policy barriers that occur between systems decrease.

As new systems develop, evaluation must be a major component. Research knowledge about children's mental health needs is in-adequate (Saxe et al., 1988). The overall effectiveness of case management services as well as the individual components need to be researched (Stroul & Friedman, 1986). The strengths, weaknesses, fiscal resources, and mandates differ across systems and communities, and these differences "must be openly explored at all levels" (Knitzer & Yelton, 1989). Examining the systems developing across the country from a solid research base would facilitate the process of determining which components are effective in maintaining children in the community and improving the quality of life for children and youth experiencing mental health difficulties.

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