

Connecting Low-Income Families to Mental Health Services: The Role of the Family Associate

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The family associate is a parent without professional mental health training who acts as a system guide to low-income families whose children have been referred to mental health services through the Early Periodic Screening, Diagnosis and Treatment program. The family associate provides emotional support, information about mental health services and community resources, and directs assistance, such as help with transportation and child care. Based on the belief that parent-to-parent support can be a powerful tool in overcoming the barriers to accessing services, the family associate role has been successfully implemented in three counties in Oregon. The family associate role and its implementation, characteristics of the families who participated, and the implications for introducing this role into traditional mental health service systems are described.

Problems related to identifying children with mental health needs and effectively connecting and them with appropriate services are perplexing to professionals in the health, mental health, and other child-serving systems. Practitioners are often discouraged when families do not follow through on a referral to a mental health clinic or when parents bring their children for one visit and never return. These phenomena have received very little research attention, and in the absence of solid information to guide theory and practice, efforts to understand these difficulties often resort to stereotypical explanations, including poor motivation and lack of interest on the part of the family, particularly if family members are characterized by poverty, lack of education, or other stigmatizing factors. There is a clear need for effective methods of promoting better access and follow through, both in starting services and in continuing services to the extent that they are needed. There also exists a parallel need for a better understanding of the dynamics involved when families do not access or fully use mental health services.

The use of a paraprofessional helper called the family associate to address the problems of access to mental health services faced by low-income families and to promote service initiation and continuance is described in this article. The particular context is Oregon's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program, which focuses on Medicaid-eligible, low-income children and their families. The family associate role has been developed and successfully implemented as part of a research and demonstration project designed to test the feasibility and effectiveness of providing short-term assistance and support to families whose children have been referred for further evaluation and/or mental health services.

MEDICAID POLICY AND EPSDT

EPSDT is a system of comprehensive and preventive health care developed to detect and correct chronic disabling conditions among children who are poor. Unlike other Medicaid programs that finance episodes of medical care without becoming involved in identifying that need, EPSDT encourages outreach, early identification, case management, and other support services to eligible families in an effort to avoid more serious health problems for children as they grow older (Jones & Nickerson, 1986). This emphasis on early identification and prevention is especially important because mental health problems are rarely identified and treated when children are young and less seriously disturbed and because the level of need for services is very high among children who live in poverty (Ontario Child Health Study, 1990; Petti & Leviton, 1986).

Since 1967, when EPSDT was authorized as a health screening program, a series of revisions have expanded the eligibility criteria, the focus on screening, and the services available. The net effect of these changes has been to mandate health treatment services, including mental health services, to an expanded population of poor children. Because EPSDT has been recognized only recently as a major source of funding for mental health services, there has been no systematic study of the use of EPSDT programs for the identification, and treatment of mental

health problems in poor children. In the field of developmental disabilities, Meisels and Margolis (1988) concluded that EPSDT Was not effective in achieving early identification or increased access to treatment for this special needs population. Although the experience of children with developmental disabilities in the EPSDT system cannot be generalized to children with mental health needs, there is no reason to believe that the latter would fare better under EPSDT without specific steps to improve the accessibility and availability of services. Certainly the barriers identified by Margolis and Meisels (1987), such as inadequate screening, untrained health care professionals, and lack of access to treatment resources, are likely to be major problems for children with emotional or behavioral problems (EBD).

Service Initiation and Continuance

Studies of service discontinuance have identified a wide variety of possible reasons for why this may occur. It has been suggested that demographic characteristics such as low income and education may be associated with service dropout (Baekeland & Lundwall, 1975; Garfield, 1986; Wierzbicki & Pekarik, 1993). However, other researchers have indicated that the demographic characteristics of clients, especially income, are not consistently related to continuance (Day & Reznikoff, 1980; Sirles, 1990; Sledge, Mores, Hartley, & Levine, 1990) or are not as important as service system issues (Goldin, 1990; Good, 1990; Sirles, 1990; Wise & Rinn, 1983). Also, in a recent meta-analysis, Wierzbicki and Pekarik (1993) reported that clients' expectations of treatment array overshadow the importance of demographic variables in predicting continuance.

Other attempts to account for dropping out of services appear to cluster into three major areas: (a) *problem characteristics* such as psychiatric symptomatology (Swett & Noones, 1989), duration of the problem (Gaines & Stedman, 1981), and type and severity of the problem (Lochman & Brown, 1980; Sirles, 1990; Viale, Rosenthal, Curtiss, & Marohn, 1984); (b) *social and environmental factors* such as distance from services or difficulty arranging childcare (Margolis & Meisels, 1987; Temkin-Greener, 1986); and (c) *barriers related to the service delivery system* such as hours of operation, configuration of services (Good, 1990; Margolis & Meisels, 1987; Sledge et al., 1990), or delays in scheduling appointments (Leigh, Osborne, & Cleland, 1984; Sirles, 1990). These findings, combined with ambiguity concerning the role of socioeconomic variables, suggest that efforts to promote continuance in services need to address functional issues related to accessibility and availability of services.

THE ROLE OF THE FAMILY ASSOCIATE

The family associate intervention was developed to address the barriers to accessing mental health services that low-income families might encounter, thus increasing the number of families who ultimately access and use such services for their children. This intervention was designed to influence several "policy-relevant" variables (i.e., circumstances or conditions that may be modified through intervention), including caregiver needs and characteristics, resource problems, and service system factors.

Caregiver needs and characteristics include attitudes and beliefs of caregivers that may inhibit entry and/or continuance in services for their children or themselves, as well as problems such as mental or physical illness. Examples include fears or concerns about involvement with mental health treatment, negative attitudes about mental health services or social services in general, and religious convictions that discourage the use of mental health services. In addition, difficulties that caregivers have in coping with multiple stresses (e.g., poverty, child's behavior, inadequate housing) may interfere with seeking or using needed services. *Family resource problems* include lack of transportation, childcare, or telephone service, or problems such as the inability to take time off from work to keep appointments. *Service system factors* may include inconvenient hours of operation, waiting lists, or lack of clear information about the purpose of the EPSDT mental health referral or the process for gaining access to services. The complex children's mental health system can be especially overwhelming to parents who are already challenged by a child's emotional or behavioral difficulties.

The key components of the family associate program are support and tangible service provided through parent-to-parent contact. The family associate models the skills necessary to maneuver within the mental health system and other community programs, thus serving as a system guide and advocate for the family and as a supportive peer for the parent. This modeling and collaborative work is designed to increase the caregivers' sense of empowerment (i.e., a feeling of mastery over one's environment) and their ability to independently navigate the service systems. The primary responsibilities of the family associate fall into the following three general categories:

1. *Providing information:* The family associate provides the parent with information about topics such as the EPSDT referral process, the mental health evaluation process, emotional and behavioral disorders in children,

available services, parents' and children's rights and responsibilities, and community resources. For example, family associates provided many parents with fact sheets about childhood disorders.

2. *Providing support:* The family associate offers the parent social and emotional support aimed at decreasing the extent to which family members feel isolated, helpless, and/or intimidated by the service delivery system. One family associate worked with many grandparents who were raising their grandchildren. Because she was also a grandparent, she was able to empathetically listen to them and help normalize their caregiving situations. The family associate also emphasizes making linkages to other parents with similar experiences and to local parent support groups.

3. *Linking to resources:* The family associate helps the parent find specific resources to address needs such as transportation and childcare that may be obstacles to accessing mental health services. He or she provides information about and helps families connect with community resources or services for which the family qualifies, and models the skills needed to locate and secure the resources. For example, one family associate discovered that parks and recreation passes were available for low-income families in her county. A component of the family associate role is access to a flexible cash fund to help families pay for supportive services. The money may be used to help families get their children to mental health services or ease their daily living burden so that emphasis can be placed on consistent participation in these services. Expenses that can be covered by the flexible cash support fund include:

1. Childcare for the family's other children;
2. Transportation costs, including public transportation, gasoline, car repairs, and automobile insurance;
3. Clothing and personal effects for family members;
4. Recreational activities to help reduce tension and provide interaction with the community;
5. Respite care to temporarily relieve parents from the stress of caregiving.

The family associate role was implemented in a research and demonstration project designed to test the effectiveness of this approach in promoting continued participation in services. The project provided a unique opportunity to develop and test an intervention designed to address problems previously linked to client characteristics (e.g., low income, lack of "system" skills) as well as environmental issues (e.g., lack of transportation, distance to services, lack of childcare). The project was structured as a quasi-experiment in which three Oregon counties implementing the family associate role were compared to four Oregon counties with no equivalent intervention. All counties had EPSDT programs and were selected in an effort to constitute two groups that were generally similar in population density and other characteristics. In this article the initial experiences and knowledge gained in the implementation phase of this project are presented.

DESCRIPTION OF FAMILIES AND CHILDREN

Target Population

Families whose children were eligible for EPSDT and who had been referred for mental health services were included in this project. In Oregon, children eligible for EPSDT are (a) in families who receive general assistance, (b) in foster care, or (c) disabled. Families were included in the project if their child was between 4 years and 18 years old; currently living with a parent, guardian, or foster parent (i.e., not in an institutional placement); had a parent or caregiver available for interviews (i.e., was not an emancipated minor); and had not participated in more than three mental health appointments resulting from the EPSDT referral. This last criterion assured that families who were working with the family associate had not yet fully established themselves in services.

Under EPSDT, children can be referred to mental health services by a private physician, a public health nurse or clinic, or a school nurse. In most cases, referrals were received at the county mental health program where the family associate was located. Upon receipt of a referral, the family associate mailed a letter and project description to the family, followed by a telephone call to verify the family's eligibility and to offer participation in the project. If the family agreed to participate, an initial interview in the family's home was scheduled as soon as possible.

Data Collection

Data were collected directly from the parent or other caregiver at both an initial interview and at a follow-up interview 3 to 4 months later. The family was paid \$25 for each interview. The initial interview was conducted by the family associate and included child and family demographics, information about previous mental health experience, the parent's perception of barriers that might make it difficult to get the child to mental health services, and completion of the behavior problems section of the Child Behavior Checklist (CBCL; Achenbach, 1991) by the caregiver.

Two additional data collection techniques were employed to measure family associate activities and services. The Ratings of Important Issues for Families (RIIFF) was developed for this project and was completed by the family associates when work with each family ended. A 16-item self-report questionnaire, the RIIFF was used to measure the family associates' perceptions of the barriers experienced by the caregivers. Each item is presented as an issue that may be important to families when they are initiating mental health services for their child and is rated on a 4-point Likert scale (1 = *not important* to 4 = *very important*). Family associates also identified issues they actually addressed in their work with each family and provided an overall estimate of the degree to which each family needed the services, based on a 4-point Likert scale (1 = *not at all* to 4 = *very much*).

The Family Associate Activity Log was developed as a project-specific document maintained by the family associates during the time they worked with each family. For each contact with, or on behalf of, a family, family associates recorded (a) the date; (b) the person contacted; (c) the type, duration, and location of the contact; (d) the type of activity(ies); and (e) comments about the contact. Any single activity or combination of six activities could be recorded: scheduling, data collection, providing intervention, finding resources, providing support, or receiving information. Family associates also reported the dollar amount and purpose of any expenditures.

Child and Family Demographics

The rate at which families chose to participate in the intervention varied across the three counties: 19 (100%), 27 (77%), and 51 (69%). Of the 31 families who declined, 9 stated they did not want family associate services because their children did not need mental health services, based on their own or a professional's assessment. Other reasons were that they did not want to be involved with another person/agency or they did not have time to work with the family associate. As of January 1994, 97 caregivers had completed the initial assessment and had worked with a family associate. Most caregivers were birth mothers (85%), were between the ages of 20 years and 39 years (75%), and either had a high school diploma (38%) or some college (40%). The children referred for mental health services included slightly more boys (60%) than girls (40%), and were primarily in the age ranges of 8 years to 12 years (45%) or 4 years to 7 years (42%). Only a small proportion of the children (13%) were in the 13 years to 18 years category. Eight percent of the children and 7% of the caregivers identified with a specific ethnic or cultural group. The annual family income for 89% of families was under \$15,000, and 76% of the caregivers reported no employment outside of the home.

The sample families lived in a variety of locations, including rural areas, small towns, and larger cities. The population of towns nearest in location to the families ranged from around 100 to nearly 113,000, and 53% of the families lived in areas where the closest town had a population of less than 20,000. Almost half (49%) lived within 4 miles of the mental health office where their children received services; 75% lived within 9 miles.

An indication of the severity of the children's behavior problems is provided by the total behavior problem *T* scores from the CBCL. Sixty-seven percent of the scores fell into the clinical (61%) and borderline clinical (6%) ranges. Sixty-nine percent of the children exhibited clinical (58%) or borderline clinical (11%) levels of externalizing behavior problems, and 6296 of the children demonstrated clinical (53%) or borderline clinical (9%) levels of internalizing behavior problems.

An understanding of parents' attitudes toward and concerns about mental health services for their children can be gained by examining the anticipated barriers that parents identified in the initial interview. Parents responded to a list of common barriers by indicating if they expected any of the items to be problematic. The most frequently identified barriers were transportation (51%), time conflicts (47%), childcare problems (45%), dislike of the therapist or treatment program (38%), disagreement with the diagnosis or treatment approach (32%), a belief that services would not help (29%), confusion about the next step (25%), and treatment refusal by the child (23%). Interestingly, no significant relationship was found between distance to the mental health office and an expectation that transportation problems would be a barrier. The percentages for the remaining expected barriers—disruption to family routine, too far to travel, discomfort with mental health services, and no need for mental health services—were all 21% or below.

SERVICES PROVIDED

Implementation

The three family associates were recruited and hired by the county mental health programs in which they were to work. All were women; one was African American. Two had previous experience maneuvering within complex service systems for their own children. The third, a parent of young children, had previous experience at the line staff level within children's mental health services. None had prior training as a mental health service provider, although all three had worked in paraprofessional or support staff positions and were familiar with the internal workings of social services.

Before data collection began, two 2-day training sessions were conducted for the family associates and their supervisors. The first session was held immediately after the family associates were hired and the second after a 3-month pilot period. The primary goals of the initial training were to provide an overview of the philosophy of the project and the family associate role, an orientation to family support literature and services, an introduction to available community resources, and a discussion of ways to implement the role and define boundaries. The training consisted of presentations, discussions, role plays, and problem-solving exercises. A number of key issues were addressed, including child abuse reporting, confidentiality, the brief nature of the intervention, the extensive needs of low-income families, and termination from the program.

During training, a focus of discussion was the Family Cash Support Fund. Emphasis was placed on working with the families to demonstrate how to get their needs met without creating a dependent relationship on the project; therefore, family associates were instructed to first take advantage of all other community options, including free services and affordable alternatives. Once these services and resources were depleted or deemed unavailable, the cash fund was to be used to enhance each family's ability to access and/or continue mental health services.

During the 3-month start-up period, the family associates were encouraged to experiment with different ways of working with families and adapting the intended services to the unique situation in each county. A special challenge of this initial phase was establishing the role of the family associate within each county's existing mental health systems.

At the second training session, the family associates shared common strategies and experiences from the pilot period and raised a number of important issues. These included establishing trust with families, dealing with the stress of listening to the caregivers describe their difficult circumstances, and addressing termination concerns. An ongoing theme was the need to clarify the distinction between the roles of the family associate and the traditional service provider.

From the beginning of the project, supervision was recognized as a crucial support for the family associates. Because each family associate was usually the first person to contact a family whose situation was unknown, it was critical that she have support and backup from a trained mental health professional in her county. Initially, supervision focused on finding local resources, learning county-specific procedures, and developing relationships with referral services and mental health providers in the county. The latter two issues were significant because the county mental health systems had never included a paraprofessional working directly with families nor had they used flexible funding to meet families' needs. Eventually, supervision shifted to a focus on the extensive needs of families involved in multiple services and with more severe circumstances. Family associates received supervision from the person responsible for monitoring EPSDT procedures and services or another qualified mental health professional in the county.

The family associates were also given opportunities to further develop their roles through discussions with each other and the research team. The project manager planned regular conference calls for the family associates to discuss their activities, find solutions for challenging situations, and provide each other with support for implementing an isolated role. However, scheduling calls in which all three family associates could be involved proved to be impossible, so most telephone support involved only one family associate. The family associates were also brought together for two day-long follow-up meetings to allow them to share experiences and exchange ideas. The research team also discussed preliminary data with them and received their feedback on role implementation.

Family Associate Activities

Each family associate worked with 5 to 10 families, and they maintained contact with them until the child had participated in three mental health appointments. This was judged to be a reasonable indicator of successfully

initiating mental health services. The duration of family associate services ranged from 3 weeks to 3 months and varied according to the availability of services. As services were terminated, new families were recruited from the most recent referrals.

The specific family associate services provided were documented through entries in the Family Associate Activity Log. Each entry listed the person with whom the contact was made, the method of contact (in person, telephone, or mail) and the types of activities. More than one activity could be recorded for each contact. Family associates made most of their contacts with a family member (87%), and contacts were most frequently made by telephone (52%) or in person (42%). Family associates provided information to the caregivers (61%), support (41%), and money (21%), and located resources (9%). All families were provided with information, 93% were given social and emotional support, 79% received money from the cash fund, and 37% were given assistance in locating resources. Family associates were not asked to give time estimates for each activity; however, they reported that the majority of their time was spent providing emotional support.

Another perspective is provided by the family associates' completion of the RIIF. This instrument assessed both their perception of the barriers experienced by parents and whether or not they provided services to address these barriers. Data for the first 71 families for whom complete data were available are presented in Table 1.

TABLE 1
Barriers Experienced and Services Received by Caregivers^a

Barrier/need	Families with barrier^b	Families receiving services for barrier
	(%)	(%)
Emotional support	82	79
Information about mental health services	62	51
Transportation	54	54
Recreation	49	41
Information about emotional disorders in children	43	31
Childcare	27	16
Clothing	23	18
Respite care	20	9
Daily living tasks	16	6
Utilities	11	9
Obtaining benefits	10	3
Contact with other parents	9	7
Food	1	0

Note. N = 71. ^aBased on ratings (RIIF) provided by the Family Associates. ^bBased on combining the ratings of *slightly important, moderately important, and very important.*

There is consistency between the barriers that family associates rated as important to families and the barriers that they reported working on with families. Emotional support, information about mental health services, and transportation were the top three in each set of ratings. The finding that family associates did not always provide services in the areas they rated as important to the families is not surprising, given the degree of the families' needs and the limitations faced by family associates. The most notable discrepancies between services provided and barriers experienced occurred in areas such as childcare, respite care, and need for information, discrepancies that most likely reflect a restricted range of available resources, particularly in rural areas.

The Family Cash Support Fund was specifically developed to help families with expenses that impeded their access to services. The categories of expenses, the number of families who received support in each category, the number of expenditures made (one family might receive funds several times for the same category), and the average amount per expenditure per category are presented in Table 2. Fifty-six of the 71 families (79%) received financial help from the fund, averaging \$132 per family. Individual families received from \$10 to \$369. The majority of expenditures were related to private or public transportation, including car repairs, tires, gas, bus tickets, and taxi service.

Family associates realized that even though a family might have had the necessary means to get to appointments, if the parent(s) were exhausted from taking care of a child with special needs, their ability to get to the mental health office was reduced. One answer to this problem was to give the parents a break by offering the child recreational opportunities (e.g., martial arts, scouting, swimming) outside of the home. This

recreation/entertainment was often substituted for the more traditional child/ respite care services that were difficult to find in most counties. Few families received reimbursement for formal childcare or respite care (see Table 2).

Family associates also reported expenditures related to daily living needs. These included providing home heating during the winter months, installing a telephone to maintain contacts with the mental health agency, and providing money for laundromat expenses. Personal effects expenditures included clothing, shoes, and haircuts for children.

Fifteen of the 71 families (21%) received no monetary support. Some families did not need the money because they had established adequate support networks (e.g., family/friends for free childcare) or because services were conveniently located (e.g., no transportation costs because the mental health appointments occurred at the child's school). Others were uncomfortable about taking money for what they believed they should be able to provide or were skeptical about the counties' willingness to pay for items such as clothes or car repairs. In addition, family associates initially were hesitant to use the cash fund because of concerns about "using it up" too soon, "bribing" families, or creating monetary dependence. As family associates became more comfortable with using the flexible fund, it became a testimony to their creativity in addressing various family needs.

**Table 2:
Summary of Expenditures from Family Support Cash Fund**

Expense category	Number of families	Number of expenditures	Avg. dollars per expenditure
Transportation—private	27	38	70.53
Transportation—public	9	14	33.93
Respite/childcare	5	6	56.83
Daily living needs	13	15	58.47
Personal effects	9	13	52.39
Recreation/entertainment	29	37	67.08

Note. N=71

DISCUSSION

The family associate role overlays a family support strategy on a mental health system organized and staffed by skilled mental health professionals. Involved in the implementation of this intervention were two major issues: the introduction of an innovative paraprofessional role into an existing service system and the pragmatic difficulties of supporting paraprofessionals in their efforts with low-income families.

System issues that appeared to be related to the implementation of the family associate role included initial misgivings with the ideas underlying this role voiced by some mental health staff, minor delays in implementing a system of referrals to the program, and the grant-funded nature and the generally low status of paraprofessionals. Each of the family associates struggled to make her role fit within the unique structure of county mental health services. The results of these efforts varied, depending on the support available within the mental health program and on other circumstances in each county. Even if there were individuals within each county who valued and promoted this paraprofessional strategy, it did not necessarily assure smooth implementation.

The pragmatic difficulties that emerge when a paraprofessional strategy is placed within a traditional mental health system are illustrated by the training and supervisory needs of the family associates. Paraprofessional training must always provide a balance between developing professional skills and capitalizing on the expertise and experience for which the paraprofessional was hired. This balance is underscored in mental health services where emotional disabilities are intertwined with issues of poverty, and paraprofessionals may encounter infrequent but dramatic crisis situations. In this project, family associates frequently saw families in their homes, away from the support offered by professional staff in the mental health offices. How to train family associates to handle all possible situations while at the same time maintaining their personal expertise as peer parents is an ongoing issue requiring further exploration.

Another concern is the type and frequency of supervision needed by family associates. Supervisors with clinical experience may lean toward discussion of "problem families" and encourage "expert" interventions rather

than empowerment-oriented activities. The experiences of this project suggest that family associates need supervision that helps them understand mental health issues while preserving their unique perspectives.

Implementation of the family associate role has allowed for a more in-depth exploration of the barriers faced by poor families in accessing mental health services. The problem of transportation to and from services was a dominant theme throughout these findings: it was identified as a barrier by most families and the family associates, and assistance with transportation was the most frequent expenditure from the flexible cash fund. Problems with transportation and the distance from mental health services, however, appear to be two separate and distinct barriers. This distinction takes on added meaning when seen in the context of rural counties with minimal public transportation. Families in rural areas who live 20 or more miles from services and who are accustomed to driving that far may not identify either transportation or distance as a barrier when they have a reliable vehicle. On the other hand, families who live much closer to the mental health agency may identify both transportation and distance as a problem because they have neither a car, nor access to public transportation and must transport several children in addition to the one that has been referred. Isolation created by lack of transportation and its ramification for service utilization clearly needs more study.

The next phase in the study will be to assess the intervention's effectiveness by examining the extent to which families and children initiate and continue in mental health services. Additional analyses will examine family empowerment and family coping strategies, and the relationship of these variables to the children's demographic and clinical characteristics. Equally important are the perceptions and experiences of the families concerning the family associate services they received. The family associate role is a unique strategy for addressing family and environmental circumstances that may interfere with access to mental health services. This approach and related strategies that introduce new roles into the system hold considerable promise for improving services to children with emotional disorders and their families.

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