DOCUMENT RESUME

ED 432 105 EC 307 310

AUTHOR Koroloff, Nancy M.; Elliott, Debra J.; Koren, Paul E.; Friesen, Barbara J.

TITLE Family Connections Research & Demonstration Project. Final Report.

INSTITUTION Portland State Univ., OR. Regional Research Inst. for Human Services.

SPONS AGENCY Oregon State Dept. of Human Services, Salem. Mental Health & Developmental Disabilities Services Div.; Substance Abuse and Mental Health Services Administration (DHHS/PHS), Rockville, MD. Center for Mental Health Services.

PUB DATE 1996-04-00

NOTE 233p.

CONTRACT MH49072-02.

PUB TYPE Reports - Research (143) -- Tests/Questionnaires (160)

EDRS PRICE MF01/PC10 Plus Postage.

DESCRIPTORS Advocacy; Children; *Emotional Disturbances; *Family Needs; *Helping Relationship; *Mental Disorders; *Mental Health Programs; *Parent Associations; Parent Education; Parent Empowerment; Program Evaluation; Social Support Groups

IDENTIFIERS Oregon; *Social Skills Training

ABSTRACT

This final report discusses the outcomes of the Family Connections Research and Demonstration Project, a project funded by the Oregon Center for Mental Health Services to study the effectiveness of an intervention designed to address the major problems related to services initiation and continuance within the children's mental health system. The intervention was delivered by Family Associates, parents without mental health training who acted as a system guide to low-income families whose children had been referred to mental health services through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. The family associate provided emotional support, information about mental health services and community resources, and direct assistance such as help with transportation and child care. A comparison of 96 families from intervention counties and 143 families from comparison counties indicated that families in the intervention group were significantly more likely to initiate children's mental health services than were those in the comparison group, that they reported higher levels of empowerment, and greater positive change in family well-being during the time they worked with the Family Associate. Appendices include relevant forms, interviews, and questionnaires. (Contains 105 references.) (CR)

FAMILY CONNECTIONS

Final Report

RESEARCH & DEMONSTRATION PROJECT

REGIONAL RESEARCH INSTITUTE for Human Services

Portland, Oregon

Regional Research Institute is affiliated with the School of Social Work at Portland State University

Family Connections Research & Demonstration Project

FINAL REPORT

Prepared By:
Nancy M. Koroloff, Ph.D.
Debra J. Elliott, Ph.D.
Paul E. Koren, Ph.D.
Barbara J. Friesen, Ph.D.

Prepared For:
Oregon Mental Health & Developmental Disabilities Services Division
State of Oregon Department of Human Services

April 1996

This report was developed with funding from the Center for Mental Health Services, Substance Abuse and Mental Health Services (Grant No. MH49072-02). The content of this report does not necessarily reflect the views or policies of the funding agencies.

EXECUTIVE SUMMARY

The Family Connections Research and Demonstration Project was funded by the Center for Mental Health Services to study the effectiveness of an intervention designed to address the major problems related to services initiation and continuance within the children's mental health system. The intervention was delivered by Family Associates, parents without mental health training who acted as a system guides to low-income families whose children had been referred to mental health services through the EPSDT program. The family associate provided emotional support, information about mental health services and community resources, and direct assistance such as help with transportation and child care. Family Associates had access to a small flexible cash fund that they could use to pay for services and supports needed by the families. Based on the belief that parent-to-parent support is a powerful tool in overcoming the barriers to accessing services, the Family Associate role was successfully implemented in three Oregon counties. Four additional counties cooperated in the research as comparison counties.

Over the three years of the project, 96 families from intervention counties and 143 families from comparison counties agreed to participate in the research. Caregivers were interviewed shortly after an EPSDT referral for mental health services was made and again at a point three to four months later. The caregivers completed a structured interview and a set of standard child and family functioning scales at both data collection points. The Family Associates provided data on their daily activities with the families and their perceptions of the barriers experienced by the families as well as the barriers their services addressed.

The sample of children referred for mental health services included primarily White (81%), male (61%), children ages 4 to 12 years old (87%). The respondents were primarily birth mothers (88%) who were unemployed (74%) with at least a high school education (79%). The majority of families had an annual income of less that $10,000 (69%) and lived less than five miles from the mental health office (47%). Group comparisons revealed that the families included in the intervention and comparison groups were not significantly different on any of the child or family characteristics measured. Additional group comparisons on the initial Child Behavior Checklist and the F-COPES scores also showed no significant differences. On the Family Empowerment Scale family sub-score, measured at the initial interview resulted in a significant differences between the two groups.

The major findings of the study revealed that families in the intervention group were significantly more likely to initiate children's mental health services than were those in the comparison group. The Family Associate intervention did not increase the likelihood that families would maintain uninterrupted attendance at clinic appointments. About 33% of both intervention and comparison groups missed no appointments and

about 23% of both groups missed more than two clinic appointments. The Family Associate intervention did not increase the likelihood that families would continue in treatment until it was completed. The dropout rate for families in this study fell between 20% (comparison families) and 24% (intervention families), a rate at the low end of the dropout rates reported in the literature.

In addition to helping families get started in mental health services, some conclusions can be drawn about the Family Associate's ability to help families improve their sense of empowerment as well as family well-being. A modest but significant difference between the comparison and intervention groups was found for family and service system empowerment, with the intervention families reporting higher levels of empowerment at post-test. Similarly, intervention families reported a significantly greater positive change in family well-being during the time they worked with the Family Associate relative to the same time period for comparison families.

One of the important contributions of this study is the clear explication of barriers families face while initiating and continuing mental health services. Some of the barriers identified were due to the family's situation, others were related to the organization of the mental health service delivery system. Families most often reported facing barriers with respect to finding respite care, transportation to services, finding appropriate recreational opportunities and emotional support. Comparison families repeated these barriers and in addition reported difficulties with accessing information about mental health services and about emotional and behavioral disorders.

Given the significant findings that emerged from an intervention of relatively narrow focus, there is considerable promise for expanded efforts in this regard. Additional outreach efforts to families, especially when coupled with modifications to the service system, may substantially improve families' chances of accessing mental health services. Most other investigators have examined accessibility from a perspective limited to family demographics and service system issues. This research affirms the importance of adopting a broader view of families' lives when addressing the problems of service accessibility.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER I
INTRODUCTION

In 1990, estimates from several counties in Oregon suggested that between 40% and 60% of the children referred to mental health services through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) process never began those services. The conditions that interfered with these children's access to services included: 1) a complex service system, 2) barriers such as lack of transportation or child care, and 3) possible low motivation to follow through on the part of families whose children's mental health problems were not severe or long-standing. In 1991, the Family Connections project was funded as a services research and demonstration project under the Center for Mental Health Services (then part of NIMH).

The Family Connections project addressed the barriers that made it difficult for low income families to access mental health services for their children. Families and children who participated in this project had been referred to mental health services through EPSDT. These families were offered the assistance of a supportive person, the Family Associate, who was a parent, had negotiated service systems on behalf of her own child, and had received special training from staff at the Portland Research and Training Center on Family Support and Children's Mental Health. A small flexible cash fund was available for use with families. The Family Associate acted as a system guide, providing information, emotional support, and help with concrete barriers such as transportation and child care for other children. This report describes the Family Associate intervention in detail and examines research questions related to the effectiveness of the intervention. The primary research question investigates whether the families who received the Family Associate services were more likely to initiate and continue child mental health services after referral.

Service Initiation and Continuance

Estimates of noncontinuance (i.e., dropout) in mental health services vary widely, depending upon factors such as the definition of dropout used and the phases of the intake and treatment process considered. Goldin (1990), for example, reported that 31% of adults who attended a psychiatric intake interview did not keep the first appointment with a therapist. Also focusing on early dropouts, Chesney, Brown, Poe, and Gary (1983) found that 53% of adults who went to a mental health clinic for at least one visit dropped out before the end of the first month. Pekarik (1991) reported that, for both public and private mental health settings, about 80% of clients terminated treatment by the tenth visit and half by the fifth visit.

Estimates of dropout rates for children in mental health settings include a high of 93% reported by one child guidance clinic (Hunt, 1961); 68.3% of children who entered

mental health treatment (Sirles, 1990); and between 25%-35% for parent training (Forehand, Middlebrook, Rogers, & Steffe,1983), group treatment for children (Mannarino, Michelson, Beck, & Figueroa, 1982), and individual child psychotherapy combined with counseling for parents (Day & Reznikoff, 1980). Most recently, Wierzbicki and Pekarik (1993) reviewed 16 studies of dropout among children and computed a mean dropout rate of 46.81% with a standard deviation of 19.76. They concluded that the definition of dropout influenced the dropout rate reported. Those studies that defined dropout as failure to attend a scheduled session reported significantly lower rates that did studies that defined dropout in terms of therapist's judgment or number of sessions completed.

The phase of treatment during which dropout is measured may also affect the rate computed. Sirles (1990) found that different predictive variables seemed to account for self-termination prior to intake as opposed to during either the diagnostic or treatment phases. In that study, a total of 68% of all individuals dropped out of services with about one third terminating at each stage of clinical contact. Clinicians were moderately successful in predicting who would drop out at intake and unable to predict drop out at other stages.

Just as the dropout rates for mental health evaluation and/or treatment vary widely, so too do the explanations offered. Attempts to account for dropping out appear to cluster in four major areas: (1) demographic variables (Baekeland & Lundwall, 1975; Garfield, 1986; Wierzbicki & Pekarik, 1993); (2) treatment variables such as severity of presenting problem (Lochman & Brown, 1980; McAdoo & Roeske, 1973; Ross & Lacey, 1961; Sirles, 1990; Tutin, 1987; Viale-Val, Rosenthal, Burtiss, & Marohn, 1984); psychiatric symptomatology (Swett & Noones, 1989), duration of the problem (Gaines & Stedman, 1981), previous treatment experience (Fiester, Mahrer, Giambra, & Ormiston, 1974; Marsh, Zabarenko, Stoughton, & Miller, 1989; Pekarik, 1985b), and referral source (Carpenter, Morrow, Del Gaudio, Ritzler, 1981; Pekarik & Stephenson, 1988); (3) social factors or family situation, including affordability (Lorefice, Borus, & Keefe, 1982; Sharfstein & Taube, 1982; Takeuchi, Leaf, & Kuo, 1988), practical barriers such as transportation and child care (Margolis & Meisels, 1987; Temkin-Greener, 1986), and accessibility (Acosta, 1980; Cohen, 1972; Graziano & Fink, 1973; Stefl & Prosperi, 1985); (4) barriers related to the service delivery system, such as availability of services (Leaf, Bruce, Tischler, & Holzer, 1987; Scott, Balch, & Flynn, 1984; Stefl & Prosperi, 1985), hours of operation and configuration of services (Good, 1990; Margolis & Meisels, 1987; Sledge, Moras, Hartley, & Levine, 1990), and delays in scheduling appointments (Leigh, Ogborne, & Cleland, 1984; Sirles, 1990).

Three major reviews demonstrate the evolution of thinking about the role that demographic variables play in influencing service dropout. Baekeland and Lundwall (1975) concluded that dropout from individual therapy by adults was most strongly correlated with several demographic factors (low economic status, female gender, and

low anxiety/depression), as well as low levels of therapist experience. In a 1986 review of 86 articles, Garfield reported that dropout rate was related to demographic variables such as lower socioeconomic status, low level of education, and minority racial status.

The most recent meta-analysis, completed by Wierzbicki and Pekarik (1993), included 125 studies of psychotherapy dropout for both adults and children. They found that variables such as minority group status, low level of education, and low socioeconomic status were associated with dropout for both adults and children. Female children were more likely to dropout of psychotherapy than were male children. They also found, however, that clients' expectations of treatment duration may overshadow univariate findings related to demographic variables. They strongly recommended that studies of adults and children be analyzed separately.

Explanations that feature client characteristics often involve income alone or socio- economic status. The literature contains many references to the relationship between low income and tendency to drop out of service (Aylward, Hatcher, Stripp, Gustafson, & Leavitt, 1985; McMahon, Forehand, Griest, & Wells, 1981; Russell, Lang, & Brett, 1987). Some recent studies suggest, however, that the demographic characteristics of clients, especially income, are not consistently related to continuance (Day & Reznikoff, 1980; Sirles, 1990; Sledge, 1990) or are not as important as service delivery system issues (Goldin, 1990; Good, 1990; Sirles, 1990; Wise & Rinn, 1983). There is, however, no evidence that low income contributes positively to service continuance.

Increased severity of problems in children appears to be related to increased service continuance. Sirles (1990) reported that children with less severe problems were more likely to drop out of service, especially if the assessment process was prolonged. Lochman and Brown (1980) found that parents who dropped out of a parent education program were initially happier with their family and their own child management skills than parents who completed the groups. This is in contrast to some studies of adult populations, where increased severity of symptoms has been related to dropping out (Chesney et al., 1983; Swett & Noones, 1989). McMahon et al. (1981) reported that parents who were depressed were more likely to drop out of parent training programs, and Pekarik and Stephenson (1988) reported that parental characteristics and motivation were related to dropout. These findings suggest that children's problems must be sufficiently serious or troublesome to provide motivation for service, but that problems such as parents' depression might interfere with the process of seeking help for themselves or their children.

A number of system variables have been identified as important to understanding service continuance, and these are particularly important because they are policy-relevant, (i.e., they may be altered by changes in policy or administrative practice). These include delays in scheduling (Leigh et al., 1984; Sirles, 1990), lack of

service continuity (Good, 1990; Good & Hendrickson, 1986; Wise & Rinn, 1983), and distance from services or transportation issues (Margolis & Meisels, 1987; Temkin-Greener, 1986). Generally, increased distance from services and lack of transportation are directly related to dropout, although Swett and Noones (1989) reported that adult clients who lived closer to services were more likely to drop out. Initial contacts with the system and experiences during the intake process appear to be particularly important. Sirles (1990) found that children were more likely to continue when a number of family members were interviewed at intake, as compared to interviewing the child only or the family as a whole only. Day and Reznikoff (1980) reported that inappropriate expectations on the part of children and families were directly related to dropping out of mental health services.

Other suggestions abound regarding ways to lower dropout rates, but few systematic studies have been conducted, and children and families are not often addressed (Pekarik, 1991). Cowan (1979) and Stringer (1978) both suggest that the EPSDT system will be most effective in identifying mental health problems in children and successfully enrolling them in service when a substantial degree of integration between health and mental health systems is achieved. Burns et al., (1983) report that health and mental health personnel believed that linking mental health services improved the provision of services in rural areas.

Rural Service Delivery

There is general agreement that people who live in rural areas are under served by the mental health community (Kelleher, Taylor, & Rickert, 1992; Lee, Gianturco, & Eisdorfer, 1974). The National Commission on Children (1990) identified a number of barriers to mental health access in rural areas, including poor economic conditions, the difficulties of attracting health personnel to isolated areas, and cutbacks in federal programs. Before reviewing the literature on the problems of access and delivery, it is instructive to discuss the problems encountered in defining "rural" or measuring the extent to which an individual lives in a rural community.

There is consensus throughout the literature that no standard, adequate method for defining rurality exists (Clayton, 1977; Mathews, 1988; Miller & Luloff, 1981; Smith & Parvin, 1973). Wagenfeld (1990) pointed out that "rural" and "nonmetropolitan" definitions are interchangeably used to identify subjects as rural. Murray and Keller (1991) also makes this distinction, providing the following definitional criteria:

> As defined by the U.S. Bureau of Census, rural populations consist of people who live in places or towns of less than 2,500 inhabitants and in open country outside the closely settled suburbs of metropolitan cities. By contrast, urban areas consist of cities with 50,000 or more inhabitants and the closely settled areas around them, as well as communities that have at least 2,500 persons but are outside those urbanized areas.

...MSA's (metropolitan statistical areas) have a total population of at least 100,000 (75,000 in New England), comprise one or more central cities with at least 50,000 inhabitants, and include adjoining areas that are socially and economically related to the central city. (p. 220)

A number of researchers have chosen to use the population density definition (e.g., Carscaddon, George, & Wells, 1990; Flaskerud & Kviz, 1984; Lee, et al., 1974; Munger, 1988), others have used the MSA criteria (e.g., Blouch, 1982; Deavers, 1992; Sherman, 1992), and others have not clearly reported the criteria used to define rurality (Burns, Burke, & Ozarin, 1983; Cohen, 1972). Murray and Keller (1991) concluded that neither of the U.S. Bureau of Census definitions satisfactorily define rurality. Apparently, other researchers have reached the same conclusion and created their own criteria. Windley and Scheidt (1983) used population density (i.e. number of people per square mile of an area) and occupational criteria (not provided) to define the level of rurality in 39 eastern Kansas counties. To define rurality, Smith and Parvin (1973) used an index with nine factors: population density; percent of persons living in rural areas; total population; percent employment in agriculture, fisheries and mining; percent of persons living on farms; average annual percent of change in population from 1940-1970; percent employment in medical and dental professions; percent employment in entertainment and recreation services; and percent employment in service work. Using a multiple discriminant analysis, Miller and Luloff (1981) found that 90% of their subjects were correctly classified as rural based on five factors: occupation, family structure, personal characteristics, religion, and residence characteristics (including residence at age 16 years). No final conclusion regarding the impact of using different definitions for rurality has been reached in the literature.

Until recently, researchers have generally concluded that people living in rural areas suffer from greater prevalence of psychological problems compounded by inadequate mental health services (Keller & Murray, 1982; Murray & Keller, 1991; Wagenfeld, 1990). The Garfinkel, Hoberman, Parsons, and Walker (1988) reported that adults living in rural areas have experienced rapid increases in suicide attempts, family violence, and depression. Higher rates of sexual abuse of children and adolescents have also been associated with rural areas (Finkelhor, 1979; Petti, Benswanger, & Fialkov, 1987). The Ontario Child Health Study (Offord, Boyle, Szatmari, Rae-Grant, Links, Cadman, Byles, Crawford, Blum, Byrne, Thomas, & Woodward, 1987) examined six-month prevalence rates of four child psychiatric disorders in both urban and rural samples. With the exception of hyperactivity, which was higher in the urban sample, no other significant differences were detected. Based on the Epidemiologic Catchment Area Program studies, Wagenfeld (1990) concluded that rates of most psychiatric disorders are higher in urban settings, although he contends that methodological concerns make this conclusion tentative. The recent social and economic changes in rural America may lead to rapidly increasing rates of mental and emotional disorders. For example, Garfinkel et al. (1988) found

increasingly higher rates of depression, suicide attempts, and suicidal ideation among rural adolescents.

The evidence regarding the paucity of mental health services in rural areas is, however, more conclusive. Wagenfeld's (1990) review found that large proportion of rural Americans are without mental health services. Human and Wasem (1991) identified economic issues as the primary factor in the limited mental health services available in rural areas. Petti and Leviton (1986) stated that mental health services for children and adolescents are particularly lacking. One reason for this is the limited number of child psychiatrists, psychologists, and other mental health professionals providing services in rural areas (Kelleher et al. 1992; Murray & Keller, 1991). Kelleher et al. (1992) reported that families may counteract the lack of mental health professionals by seeking mental health services for children within the health care sector; however, census statistics indicate that only 9% of pediatricians practice in rural areas.

Many researchers have identified accessibility to mental health services as distinctively difficult for people living in rural communities (e.g. Human & Wasem, 1991; Murray & Keller, 1991). Long distances must be traveled to reach the limited services in rural areas (Burns, et al., 1983; Gerber & Semmel, 1983; Keller & Murray, 1982). Flax, Wagenfeld, Ivens, and Weiss (1979) reported that a typical rural mental health service delivery area is 5,000 square miles and the largest of these areas is more than 60,000 square miles. In a study of the effects of distance on the use of outpatient services in a rural mental health center in Kansas, Cohen (1972) found that a distance of 30 or more miles to the center was related to a 50% to 80% reduction in utilization of services.

Attitudes toward mental health services have also been explored as a barrier related to rurality (Blouch, 1982; Burns, et al., 1983; Flaskerud & Kviz, 1983; Kelleher, et al., 1992). Lee et al. (1974) performed a general survey of 223 homes in rural areas and found that although there was a high prevalence of mental health problems among the residents, the majority sought no help. These researchers identified several factors that contributed to the limited utilization of mental health services, including fear of being identified as mentally ill and lack of understanding of the purpose of the mental health clinic. Based on special hearings held by the National Institute of Mental Health, Kelleher et al. (1992) reported "the stigma surrounding mental disorders was seen as the greatest barrier to effective mental health care for rural people with mental illness" (p.846). Human and Wasem (1991) identified factors contributing to this problem of acceptability, including a history of helping one's self, beliefs about the cause of emotional disorders and the appropriate healer, and lack of knowledge about mental disorders and services.

The evidence regarding knowledge of and attitudes about mental health treatment among rural populations is, however, not conclusive. Although Lee et al. (1974) found that lack of knowledge about the purpose of mental health treatment has been a barrier to treatment for rural populations, nine years later Flaskerud and Kviz (1983) revealed a generally high level of knowledge of the services that were available and the symptoms associated with mental illness. In a discussion of rural community mental health, Gonzales, Hays, Bond, and Kelly (1983) contended that rural populations would be more likely to utilize mental health treatment if the programs were designed to match rural values, belief systems, and resources. Gonzales et al. (1983) pointed out that higher levels of poverty and lower levels of education in rural populations may contribute to lower mental health treatment utilization rates.

Paraprofessionals in Mental Health Services

The patterns of emotional and behavioral disorders that need to be understood within the unique context of each rural area, combined with the small numbers of mental health professionals who wish to move to or remain in a more rural community leads to serious consideration of the role of paraprofessionals in mental health service delivery. A review of the literature suggests that the use of persons without professional training as an intervention strategy is not without precedent. Early efforts to involve paraprofessionals in community mental health centers concentrated on preparing them to provide therapeutic services. Beginning in the 1960's, the National Institute of Mental Health sponsored a series of paraprofessional programs, most of which were designed to provide low-cost psychotherapy to low income communities and at the same time provide employment for community residents. The few studies of clinical effectiveness compared the abilities of the paraprofessional with the abilities of professional staff (Gartner, 1981). The most common conclusion was that the paraprofessional therapist performed at least as well as, and sometimes better than, their professional counterparts (Durlak, 1973; Karlsruher, 1974). Sobey (1970) examined 10,000 paraprofessionals in 185 NIMH-sponsored programs and found that paraprofessionals performed three major functions: therapeutic, special skill training, and community adjustment. In addition, she cited five less frequent functions: case finding, orientation to services, screening, caretaking, and community improvement. One of her major conclusions was that paraprofessionals were employed "not simply because professional manpower is unavailable but rather to provide new services in innovative ways" (p. 133).

A similar pattern has emerged in education where the use of paraprofessionals as classroom aides has been extensive, especially in the special education classroom (Jones & Bender, 1993). When paraprofessionals were first employed in education, they functioned as clerical and administrative support. More recently their roles have expanded to include some of the activities reserved for teachers. Frith and Lindsey (1980) identified eight responsibilities, including administration of formal assessments, design of learning activities, modification of materials, provision of one-to-one

instruction, and support of home-school instruction.

Frith and Armstrong (1984) cited several reasons for expanding the use of indigenous workers in a variety of settings, which include the paraprofessional's versatility in working within different settings; the ability to work with several exceptionalities; an established track record in efficacy studies; cost effectiveness coupled with widespread economic concerns; and difficulties in securing qualified professional staff, particularly in rural areas. They emphasized the utility of the paraprofessional as an intermediary between the service providers (in this case teachers) and the community. Frith and Armstrong (1984) suggested that specific responsibilities of the paraprofessional should include making initial or follow-up contacts or referrals that involve community agencies and trouble-shooting on behalf of the provider when problems occur, especially with respect to communications.

Only a few studies have empirically addressed the effectiveness of the paraprofessional in the classroom. Prior to the passage of PL 94-142, studies often compared the performance of students taught by a paraprofessional to the performance of students taught by special education teachers. Since the passage of that law, research has focused on the added effect of the paraprofessional working in conjunction with the certified classroom teacher. According to Jones and Bender (1993), the few studies that exist are dated, the methodologies flawed, and the results mixed. Some researchers reported student outcome differences that favor the paraprofessionals, other researchers did not. No researchers found that student performance deteriorated with the addition of paraprofessionals to the classroom.

Health care has, perhaps, the longest history of employing paraprofessionals to assist with service delivery. The Neighborhood Comprehensive Health Centers Act in 1964 marked the beginning of the movement to employ indigenous community members in health care. Sparer and Johnson's (1971) evaluation of 33 OEO-funded neighborhood health centers found that close to 50% of all staff were paraprofessionals. Many of the centers employed paraprofessionals in housekeeping tasks; however, in eight of the centers, paraprofessionals worked as family health workers (a role previously performed by professionals) and in six centers they provided outreach services. The research conducted on paraprofessionals in the health care field during the 1960s and 70s emphasized the characteristics of the workers themselves, their training, and the availability of a career path. Little evidence exists regarding the impact of these workers.

In more recent years, reports have emerged on the use of indigenous paraprofessionals with poor women who are pregnant or who have young children. Dawson, Van Doorninck, and Robinson (1989) described an intriguing project in which paraprofessional home visitors provided parents with emotional support, information, and help in using community resources during pregnancy and the early years of the

infants' lives. In this study, the women who received home visits made greater use of professional care for their sick children than did a control group; however, there was no difference in the use of well-child care. In a similar project, the impact of paraprofessional support services on birth weight and the amount of prenatal care received was examined for low-income women (Poland, Giblin, Waller, & Hankin, 1992). In this project, the paraprofessionals were women who had been on public assistance and had successfully obtained health and human services for themselves and their infants. Participants who worked with these paraprofessionals had significantly more prenatal appointments and delivered infants with higher birth weights than did those in a comparison group.

The characteristics that make the paraprofessional valuable are broad. Austin (1978) noted that the essential value of the "indigenous worker" is the capacity to act as a bridge between the agency and the client. Implicit in this concept is the ability of the paraprofessional to communicate across many boundaries, including class lines. Thurston (1982) suggests that in mutual help experiences, professional credentials are irrelevant; in fact, they may be detrimental to the effect of the experiences. Characteristics that the helper should possess, according to Thurston, are past experience in coping successfully with the same problem and the ability to provide new information while acting as a role model.

History and Overview of 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, which finance episodes of medical care without becoming involved in identifying that need, EPSDT encourages outreach to eligible families, early identification, case management, and other support services in an effort to avoid more serious health problems for children as they grow older (Jones & Nickerson, 1986). The emphasis on early identification and prevention is especially germane to mental health problems because (a) mental health problems are rarely identified and treated when children are young and less seriously disturbed, and (b) the level of need for mental health services is very high among children who live in poverty (Offord, Boyle, & Racine, 1990; Petti & Leviton, 1986).

EPSDT was established in 1967 when Congress passed the Social Security Amendments requiring states to provide services for eligible persons under the age of 21. At that time, the program included all children receiving support under Aid For Dependent Children (AFDC), and required states to inform families of the services available and provide screening, diagnosis, and treatment to those families who requested it (Jones & Nickerson, 1986). Over the next ten years, EPSDT evolved into a comprehensive health care program for children who had previously had no medical care. Outreach and case management services were expanded and periodic schedules for screenings were established so that children would be regularly reviewed.

In 1981, the Omnibus Budget Reconciliation Act (OBRA 81) expanded the population included under EPSDT by involving all Medicaid-eligible children and youth under 21, not just those receiving AFDC support. The Omnibus Budget Reconciliation Act of 1989 (OBRA 89) again expanded eligibility to include families with incomes up to 133% of the federal poverty level. OBRA 89 also instituted more structured requirements for the establishment of periodicity schedules and mandated that reimbursement be made for all federally-allowable diagnostic and treatment services found necessary by the EPSDT screen. This included diagnosis and treatment needed to address mental illness (Tolliver, 1990).

From its inception, implementation of the EPSDT program has suffered from ambiguity in the legislation and reluctance on the part of many states to mount major portions of the program. Prior to OBRA 89, states were free to develop unique periodicity schedules for examinations and were under no obligation to publicize the existence of available benefits. In 1989, only 9% of eligible children in Oregon were screened and nationally the figure was one in three (Murray, 1992). Title XIX requires that states mount an aggressive community search for children who could use EPSDT services (Murray, 1992). Failure to do so, as well as other complaints regarding the administration of EPSDT resources, has led to lawsuits in a number of states. In Pennsylvania, families, teachers, and health care workers filed suit in federal court claiming that children of working families who were eligible for the EPSDT program were not receiving it (Rhodes, 1992). In 1990, families and advocates filed suit in Oregon because children who had been screened and referred to mental health services were placed on waiting lists rather than being treated.

Despite unevenness of the program across states, there is significant evidence that the EPSDT program has had a major positive effect on the physical health of poor children. EPSDT is now the largest federal-state preventive children's health program in the country, and the only source of third-party funds for preventive health services. Some evidence regarding the effect of EPSDT has emerged from research at the local and state levels. Keller (1983), in a study of EPSDT in Michigan, found that referral rates declined about 10% for children screened several times. Medicaid costs for all EPSDT participants were lower when compared to the Medicaid costs for EPSDT nonparticipants. Keller concluded that EPSDT participation was "associated with desirable outcomes of health status and costs" (p. 119).

Reis, Pliska, and Hughes (1984) reviewed six EPSDT demonstration and evaluation projects from the 1970's. They concluded that the projects were successful in uncovering unknown and/or untreated health conditions requiring care. Over half of conditions referred for diagnosis and treatment were previously undetected, and about half of these problems were judged to be moderate to severe. They also noted that the rate of treatment of the problems identified was low. Budetti, Butler, and McManus (1982), in a review of federally-funded health care programs for children, identified

three indicators of the relationship between the availability of Medicaid support and children's access to health care: (a) "utilization of health care by poor children now approximates that of the non-poor but did not begin to do so until after enactment of the Medicaid program" (p. 65); (b) families of children on Medicaid do identify some regular source of care at about the same rate as families of children who are privately insured; and (c) the introduction of copayments reduces the use of health care by poor families, suggesting that children who are removed from Medicaid eligibility will have access to less medical care.

In 1988, Meisels and Margolis reported that the procedures used by most states to do developmental assessments were still fragmented and ineffective. In their study of children with developmental disabilities, they found that EPSDT was not effective in identifying problems early or in increasing access to medical care. In an earlier article, Margolis and Meisels (1987) reported on a study in which the informants included EPSDT clinic directors and parents of children with developmental disabilities who had been screened through EPSDT. The authors identified three sets of barriers: (1) content barriers such as problems with the design and organization of the screening process, as well as sensitivity of the screening process to the needs of children with disabilities; (2) facilities-personnel barriers such as a lack of public awareness of EPSDT, lack of transportation, and lack of sensitivity and knowledge about developmental disabilities on the part of the health care professionals who conducted the screenings; and (3) referral barriers such as lack of qualified providers and parents' inability to pay for additional services not reimbursed by Medicaid.

While these studies did not examine children with serious emotional disabilities directly, there is no reason to believe that these children would fare better under EPSDT without specific steps to improve accessibility and availability of services. Certainly, inadequate screening, untrained health care professionals, and lack of access to treatment resources are likely to be major problems for children with serious emotional disabilities. Since the mandate to include both mental health screening and treatment has only recently been enforced, no research is available that examines the experiences of children with serious emotional disabilities and their families in the EPSDT process.

As a beginning step, Small (1991) examined the obstacles to children receiving mental health services under Medicaid and concluded the barriers are primarily due to state policies. He contended that state policies erect barriers to access through a) eligibility requirements and decisions about which groups of children the states will include, b) the services the states choose to provide and the setting in which they must be provided, and c) the choice of ways to reimburse participating providers. The combination of a restrictive definition of eligibility combined with a non competitive provider rate and a cumbersome reimbursement process can adversely effect access to services for poor children.

Context of the Project

In Oregon, the EPSDT process was restructured with the goal of providing a distinct pathway to mental health services for children referred for mental health services through the (EPSDT) screening process, commonly called a medicheck. The pathway provided for a uniform assessment of children with suspected mental health problems and the development of a treatment plan from this assessment. Under the 1990 plan, the services provided to these children were monitored by a Treatment Planning Coordinator (TPC). The TPC also led the Interagency Services Planning Teams that were responsible for the treatment planning for children with serious emotional disorders who were at risk of out-of-home placement or may have required treatment from several systems. Additional modification continues to be made to this referral process.

Research and experience at the national level indicates that children with mental health problems need varying degrees of treatment services. Using a prevalence rate of 17% (Institute of Medicine, 1989), the number of Oregon Medicaid children who needed some form of mental health service was estimated at 16,013 in 1990. Of these, 1,241 were already receiving State-funded mental health treatment services. In 1990, it was estimated that only about 50% of the children in need of mental health intervention would be identified during the EPSDT screen. This resulted in an estimated pool of 6,766 Medicaid children eligible for evaluation and treatment during 1990.

In 1990, available estimates suggested that as high as 60% of clients who were referred for mental health evaluation and services followed through to the initial evaluation. These estimates suggested that a large group of children in need of mental health services were not receiving those services. As a result, the Family Connections Project was developed to implement and evaluate the effectiveness of an intervention created to increase the likelihood of a child initiating mental health services after being referred for those services through EPSDT. More specifically, the purpose of the intervention was to reduce the barriers experienced by low income families who are just getting started in children's mental health services. The next chapter provides a detailed description of this intervention.

CHAPTER II
FAMILY ASSOCIATE INTERVENTION

The Family Connections Project was designed to address the major problems associated with children's mental health service initiation and continuance identified in the literature. These problems are (a) navigating within a complex system, (b) experiencing barriers such as lack of transportation or child care and long distances to services, and (c) being possibly less motivated to follow through when a child's problem is not severe or long-standing. Based on the research evidence demonstrating the possible impact of paraprofessionals, the Family Associate role was created to utilize parent paraprofessionals to impact these problems.

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 mental health services for their children. More specifically, the intervention was designed to influence several "policy-relevant" variables (i.e., circumstances or conditions that may be modified through intervention) including caregiver needs, resource problems, and service system factors.

A large portion of the following description of the Family Associate role is previously published material (Koroloff, Elliott, Koren, & Friesen, 1994) that has been reprinted by permission from PRO-ED, Inc.

The Role of the Family Associate

The key components of the intervention were support and tangible service provided through parent-to-parent contact. The Family Associate modeled the skills necessary to maneuver within the mental health system and other community programs, serving as a system guide and advocate for the family and as a supportive peer for the parent. This modeling and collaborative work was designed to increase the caregivers' sense of empowerment (i.e., a feeling of mastery over one's environment) and to increase her/his ability to independently navigate the service systems. The primary responsibilities of the Family Associate fell into three general categories: providing information, providing social and emotional support, and linking the family to community resources and services.

The Family Associates had access to a flexible cash fund to aid them in helping the families pay for supportive services. The money was used for those services or items that the families needed to get their children to mental health services or to ease their daily living burden so that emphasis could be placed on consistent participation in mental health services. Expenses for which the flexible cash support fund were used included:

1. Child care, especially for the family's other children while the referred child attended appointments.

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 the child, parent, and/or family reduce tension and interact with the community.

5. Respite care to relieve parents from the ongoing responsibility for taking care of children with an emotional and/or behavioral disorder.

Implementation of the Family Associate Intervention

The Family Associates were recruited and hired by the county mental health programs in which they worked. The three Family Associates were women, two of whom had previous experience maneuvering within complex service systems for their own children. The third Family Associate was the parent of young children who had previous experience receiving public assistance herself. One of the Family Associates was African American. None of the three 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. The Family Associate in the largest county was full-time and worked with approximately 10 families at one time, whereas the other Family Associates in the smaller counties were half-time and worked with approximately five families at one time.

Before data collection began, two multiple-day training sessions were conducted for Family Associates and their supervisors. The first training session was held immediately after the Family Associates were hired (June 1992), and the second after a three month pilot period (October 1992). 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. An additional focus of discussion was on 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, the Family Associates were instructed to first take advantage of all other community options, including free services and affordable alternatives.

During the three-month startup period, visits were made by the research team to each county to finalize details about the recruitment of families, the process of referring families to the Family Associates, and the manner in which the Family Associate role

had been implemented and had evolved within each county. 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.

At the second training, the Family Associates shared common strategies and experiences and raised a number of important issues based on the three-month trial period. These issues included the challenge of establishing trust with families, dealing with the stress of listening to the caregivers describe their difficult circumstances, and termination concerns. An ongoing theme during this training was the need to clarify the relationship between the Family Associate role and the traditional provision of mental health services. The rest of the training addressed data collection procedures.

A Family Associate Training Manual was created (see Appendix A), which provides a detailed presentation of the material covered in the trainings described above.

From the beginning of the project, supervision was recognized as a crucial support to the Family Associate role. Because the 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. The project was designed such that the supervision was provided either by the person responsible for monitoring EPSDT procedures and services or by another qualified mental health professional in the county. Over time, the Family Associates' supervision needs changed. Initially, supervisory discussion focused on finding local resources, learning county-specific procedures, and developing relationships with referral sources and mental health providers in the county. The last two issues were significant because the county mental health systems had not included a para-professional working directly with families nor had they used flexible funding to meet families' needs. Eventually, supervision shifted to a focus on the global needs of families who were involved in multiple services and whose circumstances were more severe. The greatest difficulty was making sure that the Family Associates received a sufficient amount of supervision within the county mental health program. Feedback from the Family Associates indicated that they had to seek out this supervision because their supervisors were overwhelmed with other responsibilities and were not given any release time for this project. This resulted in the Family Associates relying on the telephone support from the research Project Manager more than was anticipated.

The Family Associates were also provided with opportunities to further develop their roles through discussions with each other and the research team. The Project Manager planned regular conference calls so that the three Family Associates could discuss their activities, problem solve about challenging situations, and provide each other with support for working in an innovative but isolated role. Scheduling calls in which all three Family Associates could be involved, however, proved to be difficult, so

most telephone support involved only one Family Associate. The Family Associates were also brought together for two day-long follow-up meetings to provide them with an opportunity to share experiences and to exchange ideas about working with families. These meetings were also used by the research team to discuss preliminary data with the Family Associates and to receive their feedback on the implementation of the Family Associate role.

Throughout the project, issues regarding the implementation and support of the Family Associates were raised. During the hiring process, the counties were experiencing a reduction in force which resulted in first consideration of internal candidates. The effort to avoid layoff of current employees reduced the selection pool and, as a result, their ability to locate parents who had substantial experience obtaining mental health services for their children with emotional and/or behavioral disorders. After they began providing services, each Family Associate struggled with the use of the flexible fund because it was a new concept for the county fiscal managers. It was necessary for the Project Manager to help the county fiscal managers understand that the Family Associates needed quick access to the fund and the freedom to spend the money in innovative ways (e.g., paying for car insurance, buying clothing, paying off utility bills). Other issues reflective of the difficulty of integrating an innovative role into traditional mental health programs included not adequately providing one of the Family Associates with office space and forcing another Family Associate to compete for use of a limited number of county cars (she was hired with the knowledge that she did not own a car).

As the project progressed, the Family Associates became more comfortable with their role and the county mental health programs incorporated their services more fully into the existing program structure. Although the implementation issues listed above were never fully resolved, the Family Associates found creative ways to help their families reduce barriers to mental health services and to access resources within the communities.

Research Questions

The primary goal of the Family Associate intervention described above was to reduce the barriers to initiating and continuing children's mental health services experienced by caregivers. More specifically, the research questions guiding this study were the following:

1. Did the Family Associate services produce positive outcomes on the following three aspects of children's mental health services:
   a. initiation
   b. attendance
   c. continuance?

2. Did the Family Associate services improve the family's sense of empowerment (i.e., a feeling of mastery over one's environment)?

3. Did the Family Associate services improve the family's problem solving?

4. What barriers to children's mental health services did the Family Associate help with? What other barriers to services did the families experience?

5. How did the families feel about the Family Associate services?

6. How was the flexible fund used? Specifically,
   a. What was the average amount spent per family?
   b. What products and services did the money purchase for the families?
   c. Did access to the flexible fund make getting the children to mental health services easier?

For the purposes of this study, a family was defined as having initiated children's mental health services if at least one appointment was attended after the EPSDT referral was made. The variable of continuance was defined as still receiving treatment at the point of the follow-up interview. Families were also considered continuers if the therapist decided that treatment was completed or if the family decided to discontinue mental health services because the child had improved and no longer needed treatment. Previously in this report and in later sections, the term dropout is used to signify the opposite of the continuance variable. Dropout was defined as discontinuing children's mental health services before the follow-up interview without therapist or family discussion that treatment was no longer needed.

The next chapter provides a detailed account of the research method employed in the Family Connections Project, followed by the chapter that presents the impact of the Family Associate intervention and other findings from the Family Connections Project.

CHAPTER III
METHODS

Description of the Study Sites

Presented below are descriptions of the seven counties that were included in the Family Connections Project. (The rationale for the selection of these study sites is contained in the *Research Design* section of this chapter and the geographical location of the counties may be found on the map of Oregon provided in Appendix B). The figures listed in Table 1 were derived from 1990 Oregon Census statistics. Although each county mental health program is responsible for administering the EPSDT program, each program's approach to the EPSDT process was characterized by distinctive features which are included in the descriptions below.

Table 1
County Descriptive Statistics (Oregon 1990 Census)

			0-17 Year Olds		18-21 Year Olds		% Of State Pop.	
County	County Pop.	Largest City	Total Pop.	EPSDT-Eligible	Total Pop.	EPSDT-Eligible	Total Youth	Minority Youth
Lane	282,912	Eugene 112,669	71,693	13.9%	21,080	4.4%	9.9%	6.5%
Washington	311,554	Beaverton 53,310	89,009	4.4%	16,738	7.3%	11.3%	12.4%
Lincoln	38,889	Newport 8,437	9,277	13.0%	1,314	5.4%	1.1%	0.7%
Polk	49,541	Dallas 9,422	14,310	9.1%	3,920	3.5%	2.0%	2.2%
Union	23,598	LaGrande 11,766	6,699	11.5%	1,649	6.3%	0.9%	0.4%
Malheur	26,038	Ontario 9,392	10,230	15.2%	1,811	7.0%	1.3%	3.5%
Marion	241,500	Salem 111,575	67,559	9.9%	14,468	4.4%	8.8%	12.8%

Lane County ranks third in population of the 36 Oregon counties and is located on the western side of the state. Its 4,620 square miles extend from the Pacific Ocean to the Cascade mountains, is composed of large areas of agricultural and timber lands, and contains Oregon's second largest city, Eugene. Lane County represented one of the two most populated counties in this study and provided both intervention and comparison data. The county Mental Health Program in Eugene was one of a dozen providers of EPSDT mental health services. Families and children went directly from

the EPSDT referral source to the provider of their choice without contact with the county program.

Washington County has the second largest population in the state, is located in northwestern Oregon, and is close to Portland (population 437,319), the largest city in Oregon. The county's total area is 1,727 square miles, spanning both metropolitan and farming areas. Washington County was the other most populated county in the study and provided comparison data. The county Mental Health Program in Hillsboro (population 37,520) acted in an administrative capacity only, with most EPSDT-supported mental health services delivered by three large community mental health agencies.

Lincoln County ranks 17th in population in Oregon and is a coastal county covering 992 square miles, located north of the west-most portion of Lane county. Lincoln County was one of the two counties considered rural but within driving distance of children's mental health services. This county provided intervention data. Lincoln County Mental Health Program, located in Newport, received the majority of its EPSDT referrals from the Public Health program, housed within the same building, and was the primary provider of EPSDT mental health services for the county.

Polk County has the 16th largest county population in Oregon, is located in the northwestern part of the state, and includes farm land and coastal mountains. The largest city in Polk County is Dallas (population 9,703); however, the state capital and third largest Oregon city, Salem (population 111,575), is on the eastern border of this county. This county provided comparison data and was the other rural county within driving distance of children's mental health services. The Polk County Mental Health Program in Dallas directly received many requests for services, then initiated the EPSDT physician referral process. Mental health services were provided by Polk County Mental Health, a community mental health center, and two private clinicians.

Union County ranks 23rd in population in the state, is located in the northeastern portion of Oregon, and covers 2,038 square miles. This was one of the two counties in the project considered the most sparsely populated and the most isolated from specialized children's mental health services found in the Portland area. Union County provided intervention data for this project. The Union County Mental Health Program, located in LaGrande, had become so well-known within the community that contacts were primarily made with this Program prior to the EPSDT physician referral. The Mental Health Program was the primary mental health services provider in the county.

Malheur County is located on the extreme southeastern portion of the state. Geographically, it is the second-largest county in Oregon with 94% of its 9,926 square miles being rangeland; however, its population ranks 20th out of 36 counties. Its

proportion of Hispanic children represents one of the highest in Oregon (22.2%) and constitutes 5.0% of the state's Hispanic youth population. Malheur County provided comparison data and was the other sparsely populated and isolated county in the project. The Mental Health Program, located in Ontario, provided general mental health services for this county, with specialized treatment performed by subcontracted agencies.

Marion County has the fifth largest county population and is located in the northwestern quadrant of Oregon, sharing its western border with Polk County. The state capital, Salem (population 111,575) is Marion County's largest city, covering 745 square miles. Midway through this project, Marion County was added as an additional source of comparison group data due to the unexpectedly low EPSDT referral rate in the other comparison counties. The Mental Health Program is primarily responsible for evaluating EPSDT-referred children, with the majority of the mental health services provided by seven subcontracted agencies.

Subjects

The intent of the project was to evaluate the needs of families who were just getting started in children's mental health services and, in particular, those families in which the parent or Caregiver was the person responsible for making sure that the child attend her/his appointments. Families were included in this project if:

1. A child was referred for mental health services through the EPSDT medicheck process.

2. The referred child was 4 to 17 years old.

3. The referred child was not in an institutional placement (e.g., residential treatment, correctional facility, or psychiatric hospital).

4. A parent was involved in the management of the child's mental health services and was available for the research interviews.

5. The referred child had participated in no more than three mental health services appointments.

In addition to excluding families for not meeting the preceding criteria, 31 intervention and 45 comparison families chose to not participate in the project when initially contacted by telephone. The primary reasons given for not participating were not having enough time, not wanting to be in a research project, or not wanting the Family Associate services (intervention families only). Data was not available from the smallest comparison county (Malheur) regarding the families who chose not to participate in the project.

Of the 296 families who agreed to participate in the Family Connections Project, 239 were included in the final sample on which analyses were performed. Families were excluded for the following reasons:

1. No follow-up interview data was available because the family could not be located or the respondent refused to continue participation in the project (n=14).

2. The respondent was a foster parent for the referred child. Foster families were initially included but later removed from the analyses because their situations were different from other families. Foster parents often had sufficient support from Children's Services Division, had extensive previous experience negotiating within the mental health system, and/or were not significantly involved in the management of the child's mental health services (n=16).

3. The family was determined to be ineligible based on information gathered during the initial interview (n=12).

4. Negligible Family Associate services were provided. In some cases, families who indicated interest in Family Associate services received few or no services after the initial interview. This was often due to difficulties making contact. These families were removed from the analyses because they had received an insufficient level of the intervention (n=15).

Frequencies of selected demographic characteristics for the 96 intervention families, 143 comparison families, and both groups combined (n=239) are presented in Table 2. Looking at the total sample, the respondents in this study were primarily birth parents (90%), single parents (69%), and educated at the high school level or higher (79%). Over half of the children who were referred for mental health services were male (61%), with the majority being Caucasian (81%) and 4 to 12 years old (88%). Over two-thirds of the families had an annual household income of less than $10,000 (69%) and an annual family income of less than $3,000 per person (71%). Approximately half of the families relied on public assistance as their primary source of income (52%), with another quarter of the families relying on employment (26%). Most of the families lived within 9 miles of the mental health center to which they were referred (74%) and self-identified as living in an urban area (69%).

Table 2
Family Characteristics

	Intervention (N=96)	Comparison (N=143)	Both Groups (N=239)
Child's Gender:			
Female	38.5% (n=37)	39.9% (n=57)	39.3% (n=94)
Male	61.5% (n=59)	60.1% (n=86)	60.7% (n=145)
Child's Age:			
4-7 years	43.7% (n=42)	49.7% (n=71)	47.3% (n=113)
8-12 years	43.7% (n=42)	37.8% (n=54)	40.2% (n=96)
13-18 years	12.5% (n=12)	12.6% (n=18)	12.6% (n=30)
	M = 9.3 yrs.	*M = 8.7 yrs.*	*M = 8.9 yrs.*
Child's Race:			
White	82.3% (n=79)	79.7% (n=114)	80.8% (n=193)
Nonwhite	17.7% (n=17)	20.3% (n=29)	19.2% (n=46)
Respondent's Relationship to the Child:			
Birth Mother	87.5% (n=84)	88.1% (n=126)	87.9% (n=210)
Birth Father	3.1% (n=3)	1.4% (n=2)	2.1% (n=5)
Stepmother	0.0% (n=0)	0.7% (n=1)	0.4% (n=1)
Adoptive Mother	0.0% (n=0)	2.1% (n=3)	1.3% (n=3)
Grandmother	5.2% (n=5)	4.2% (n=6)	4.6% (n=11)
Grandfather	1.0% (n=1)	0.7% (n=1)	0.8% (n=2)
Other	3.1% (n=3)	2.8% (n=4)	2.9% (n=7)
Respondent's Marital Status:			
Single Parent	74.0% (n=71)	65.0% (n=93)	68.6% (n=164)
Married	26.0% (n=25)	35.0% (n=50)	31.4% (n=75)
Respondent's Educational Level:			
No High School Diploma	21.9% (n=21)	21.0% (n=30)	21.3% (n=51)
High School Diploma	37.5% (n=36)	29.4% (n=42)	32.6% (n=78)
Beyond High School	40.6% (n=39)	49.7% (n=71)	46.0% (n=110)
Caregiving Burden (# Children <13 yrs.):			
0	4.2% (n=4)	1.4% (n=2)	2.5% (n=6)
1	20.8% (n=20)	24.5% (n=35)	23.0% (n=55)
2	35.4% (n=34)	40.6% (n=58)	38.5% (n=92)
3	26.0% (n=25)	21.0% (n=30)	23.0% (n=55)
4	9.4% (n=9)	10.5% (n=15)	10.0% (n=24)
5+	4.2% (n=4)	2.1% (n=3)	2.9% (n=7)
	M = 2.3 children	*M = 2.2 children*	*M = 2.3 children*
Help with Caregiving:			
Yes	47.9% (n=46)	58.7% (n=84)	54.4% (n=130)
No	52.1% (n=50)	41.3% (n=59)	45.6% (n=109)

Table 2 (cont.)
Family Characteristics

	Intervention (N=96)	Comparison (N=143)	Both Groups (N=239)
Annual Household Income:			
<$10,000	70.8% (n=68)	67.1% (n=96)	68.6% (n=164)
$10,000-$19,999	21.9% (n=21)	26.6% (n=38)	24.7% (n=59)
$20,000+	7.3% (n=7)	6.3% (n=9)	6.7% (n=16)
Annual Family Income Per Person:			
<$2,000	27.1% (n=26)	23.1% (n=33)	24.7% (n=59)
$2,000-$2,999	44.8% (n=43)	48.2% (n=69)	46.9% (n=112)
$3,000-$4,999	19.8% (n=19)	21.0% (n=30)	20.5% (n=49)
$5,000+	8.3% (n=8)	7.7% (n=11)	7.9% (n=19)
	M = $2,886	*M = $2,889*	*M = $2,888*
Primary Source of Family Income:			
Employment	20.8% (n=20)	28.7% (n=41)	25.5% (n=61)
Public Assistance	57.3% (n=55)	49.0% (n=70)	52.3% (n=125)
Social Security	6.3% (n=6)	2.1% (n=3)	3.8% (n=9)
Foster Care	0.0%	1.4% (n=2)	.8% (n=2)
Child Support	2.1% (n=2)	1.4% (n=2)	1.7% (n=4)
SSI	8.3% (n=8)	10.5% (n=15)	9.6% (n=23)
Retirement	0.0%	2.1% (n=3)	1.3% (n=3)
Unemployment	2.1% (n=2)	1.4% (n=2)	1.7% (n=4)
Educational Funding	0.0%	1.4% (n=2)	.8% (n=2)
Other	3.1% (n=3)	2.1% (n=3)	2.5% (n=6)
Distance To The Mental Health Office:			
≤1 mile	19.8% (n=19)	18.2% (n=25)	18.9% (n=44)
2-4 miles	30.2% (n=29)	26.3% (n=36)	27.9% (n=65)
5-9 miles	24.0% (n=23)	29.2% (n=40)	27.0% (n=63)
10-19 miles	13.5% (n=13)	14.6% (n=20)	14.2% (n=33)
20+ miles	12.5% (n=12)	11.7% (n=16)	12.0% (n=28)
	M = 7.6 miles	*M = 7.6 miles*	*M = 7.6 miles*
Population Type:			
Urban	63.5% (n=61)	70.6% (n=101)	67.8% (n=162)
Rural	36.5% (n=35)	29.4% (n=42)	32.2% (n=77)
Past MHS for Referred Child:			
Yes	24.0% (n=23)	34.3% (n=49)	30.1% (n=72)
No	76.0% (n=73)	65.7% (n=94)	69.9% (n=167)
Past MHS for Respondent:			
Yes	54.2% (n=52)	60.1% (n=86)	57.7% (n=138)
No	45.8% (n=44)	39.9% (n=57)	42.3% (n=101)

Research Design

The primary comparison in the research design involved two conditions, one an intervention condition characterized by the use of Family Associates to augment usual mental health services, and the other a control condition consisting of usual county mental health services only. No condition involved the withholding of services; rather, the research added a component to the services families would have otherwise received under EPSDT. As is shown in Figure 1, all families participated in an initial interview, followed by Family Associate services for the intervention group or an equivalent three to four month period of time for the comparison group. A follow-up interview was then conducted with all families. Statistical analyses were used to compare the intervention and comparison groups on a number of variables considered likely to change as a result of the use of Family Associates.

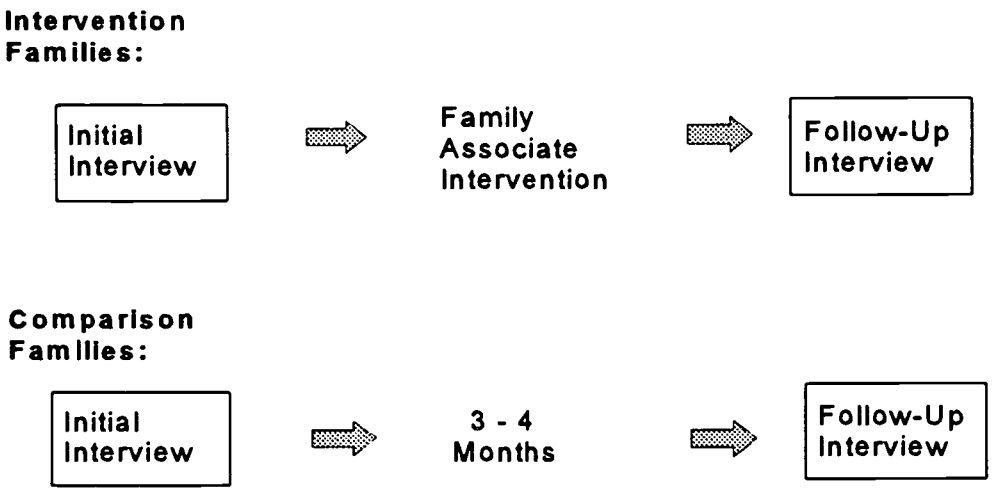


Figure 1. Research design of the Family Connections Project.

The assignment of counties to either the intervention or comparison groups was made randomly from pairs of matched counties that were approximately equal in population density and proximity to metropolitan areas with extensive and specialized mental health services. The county pairs were, starting with the most densely populated, Lane and Washington, Lincoln and Polk, and Union and Malheur. As noted earlier, Marion County was added midway through the project to increase the subject pool and was considered a moderately to highly populated county. The intervention group included families from Lane (n=50), Lincoln (n=23), and Union (n=23) counties. The comparison group included families from Lane (n=37), Marion (n=60), Washington (n=22), Polk (n=15), and Malheur (n=9) counties. Recruiting families for both

intervention and comparison groups in Lane county allowed a within-county test of the intervention condition that explicitly controlled for variation due to the organization and delivery of the county mental health services.

Procedures

Procedures for obtaining the EPSDT referral information were established separately with each of the seven counties participating in the Family Connections Project. Referrals were usually collected at medical facilities, schools, mental health agencies, the county mental health and health programs, or a combination of these sites, depending upon the primary referral source(s) for a given county. The proposed EPSDT model (see Appendix C for diagram), which identified the medicheck screening by a medical professional as the initiation point for children referred for mental health services, was modified in some counties. For the purposes of this study, we included children who were referred through the EPSDT screening process, as well as those who were EPSDT-eligible but initiated mental health services prior to the medicheck. In Lane County, which included both intervention and comparison samples, the Family Associate received the referrals and contacted families only if she had an opening in her caseload. All other referrals were given to the research interviewer to contact and engage as comparison families. After the Family Associate intervention was discontinued, all EPSDT referrals received in Lane County were contacted by the research interviewer for recruitment into the comparison group.

Upon receipt of a referral, the Family Associate (intervention counties) or the research interviewer (comparison counties) mailed an introductory letter and flyer to the family (Appendix D), followed by a telephone call to further explain the project (see Appendix E for the Initial Telephone Contact Script). If the family agreed to participate, an appointment for the initial interview was made, with the option of the interview taking place at the Caregiver's home for her/his convenience. Upon arriving at the Caregiver's home or alternate location, the Family Associate or research interviewer secured the Caregiver's signed consent (Appendix F) to participate in the research demonstration project. The initial interview (Appendix G) and associated questionnaires (Appendix H) were completed in approximately 1½ hours. The Caregiver was then paid $25 for providing the information. Once the data were collected, the research interviewer ended the visit, whereas the Family Associate usually began discussing the Family Associate services with the Caregiver.

The Family Associates worked with the families until the referred child had participated in three mental health appointments. Throughout their work with the families, the Family Associates recorded the details of their contacts (Family Associate Activity Log, Appendix I). When work with each family ended, the Family Associates provided a rating of the families' barriers to mental health services (Ratings of Important Issues for Families, Appendix I).

Three to four months after the first interview, the research interviewers contacted each family by telephone (see Appendix E for the Telephone Script for Follow-Up Interviews) or by letter to schedule the follow-up interview. It was estimated that the average time from medicheck screening to the first contact with the mental health program would be two to six weeks. Three to four months allowed the mental health services to be initiated, an evaluation to be completed, and treatment to begin. At this data collection point, the parents were interviewed again (Appendix G) and completed a second set of the same questionnaires, as well as a project-specific questionnaire addressing barriers to services (Appendix H). For doing this approximately 1½ hour assessment, each parent received another $25.

Sources of Data

The data collection protocol for the Family Connections Project included both widely-used and newly-developed measures. The former provided a link with other studies and avoided the costs and uncertainties incurred with new instrument development. Because of the variables explored, it was necessary to develop some new measures for this project. By taking a measurement approach that used new and established measures, information was gathered both in a commonly understood context and from a different, more innovative perspective. Additionally, all of the questionnaires were translated into Spanish and Spanish-speaking interviewers were available to perform the initial and follow-up interviews, in order to meet the needs of the large Hispanic population in Oregon. Presented below are brief descriptions of each of the assessment tools used (refer to Appendices G and H for samples of each measure) followed by a summary of the constructs measured by each of these assessment tools (see Table 3).

The *initial interview* was developed to gather child and family demographics; previous mental health services received by the child currently referred for services and the respondent her/himself, as well as the respondent's satisfaction with those services; barriers to mental health services previously experienced; the respondent's experiences throughout the current referral process; and barriers expected regarding the services for which the child was referred.

The *follow-up interview* measured changes to the child and family demographics; the mental health services the child and/or the family received, their satisfaction with those services, and barriers to the services experienced by the family; utilization and assessment of the Family Associate services (intervention families) or help the family could have used to facilitate the process of initiating mental health services for their child (comparison families). Respondents were also asked to complete a graph of their family problem solving at three points in time: initial assessment, completion of the Family Associate services or two months ago (depending on group membership), and follow-up assessment.

The *Child Behavior Checklist/4-18* (CBCL; Achenbach, 1991) was used to measure the level of each child's behavior problems at both assessment points. This is a 113-item three-point Likert rating scale of child behavior from the perspective of the child's parent. The parent is asked to indicate whether a given behavior is "not true", "somewhat or somewhat true", or "very or often true" for their child. It is developmentally normed for children aged 4-18 years, and factors into nine clinical scales (withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent behavior, aggressive behavior, and sex problems). The CBCL was standardized on a sample of 4,220 clinically referred and nonreferred boys and girls aged 4 to 18 years, divided into two gender groups and seven age groups. Analyses revealed significant differences ($p < .01$) between referred and nonreferred children on all items except five. The total behavior problems, and the two broad band categories, internalizing and externalizing behavior problems, were the only scores examined in this study.

Family functioning was measured at both assessment points with the *Family Crisis Oriented Personal Evaluation Scales (F-COPES;* McCubbin, Olson, & Larsen, 1981). The F-Copes is a 30-item self-report scale used to identify problem-solving and behavioral strategies used by families in difficult or problematic situations. The F-COPES asks the respondent to consider each item in regard to the prompt, "When we face problems or difficulties in our family, we respond by:", and utilizes a five-point Likert response scale ranging from "Strongly Disagree" to "Strongly Agree". Factor analyses on the data gathered on the normative sample of 2,582 respondents revealed five subscales: Acquiring Social Support (α=.83), Reframing (α=.82), Seeking Spiritual Support (α=.80), Mobilizing Family to Acquire and Accept Help (α=.71), and Passive Appraisal (α=.63). The internal reliability for the entire scale is .86. Test-retest reliability over a four-week interval (n=116) is high, with coefficients ranging from .61 to .95 (mean=.77) for the five subscales, and .81 for the entire scale. A factor analysis performed on the data from this project revealed similar factor and total scale internal consistencies, as well as a sixth factor: support from neighbors (α=.74). Since this factor had been present in early factor analyses published by the scale authors, it was included in the analyses for this project.

The *Family Empowerment Scale (FES;* Koren, DeChillo, & Friesen, 1992) is a 34-item self-report scale that was used to measure the level of the respondent's sense of empowerment at both assessment points. The respondent is presented with a five-point Likert scale for each item, ranging from "Not True At All" to "Very True." The answers are grouped into three empowerment subscores: Family, Service System, and Community/Political. Using a sample of 440 respondents who were parents of children under 21 years of age, the FES demonstrated high levels of internal consistency. Reliability coefficients were as follows: Family, α=.88; Service System, α=.87; Community/Political, α=.88. Test-retest reliability over a three to four week interval (n=107) was high, with coefficients ranging from .77 (Service System) to .83 (Family) to .85 (Community/Political).

The *Family Barriers Scale* (FBS) is a 16-item self-report measure that was developed for this project to capture the barriers to children's mental health services experienced by the respondent. It presents 13 areas that might be important to a family when initiating or continuing mental health services for a child and, if not sufficiently satisfied, would create barriers to service involvement. These areas included Transportation, Child Care, and Information About Mental Health Services. The respondent was instructed to rate each area's degree of importance on a four-point Likert scale (1=Not Important, 4=Very Important). For the intervention families, this questionnaire included two additional tasks. One asks the respondent to "Identify the issues you worked on with your Family Associate" by circling the relevant item numbers. The other task requested the respondent's assessment of how much the Family Associate services, in general, were needed by their family. This was done by presenting the respondent with a four-point Likert scale ranging from "Not At All" to "Very Much."

The *Ratings of Important Issues for Families* (RIIFF) is a 16-item self-report measure developed for this project to capture the Family Associate's perspective of a family's barriers to service involvement. It was completed by the Family Associate at the end of her involvement with each family and from which the Family Barriers Scale was adapted. Like the FBS, it asks the Family Associate to consider the degree of importance each of the areas listed had for the family, by responding to a four-point Likert scale. It also asks the Family Associate to "Identify the issues you worked on with this family" and rate "How much did this family need the Family Associate services?" using a four-point Likert scale ranging from "Not At All" to "Very Much."

The *Family Associate Activity Log* was created to document the general types of services provided by a Family Associate over the course of her involvement with each family. The Activity Log included the date of the contact, the person contacted, and the type (telephone, in-person, or other), duration, and location (office, home, or other) of the contact; the type of activity; and comments about the activity. The types of activities that could be recorded were Scheduling, Data Collection, Cash Support Fund, Providing Information, Finding Resources, and Providing Support. Whenever the Cash Support Fund was accessed, the dollar amount and the purpose of the expenditure was recorded. The Family Associates were trained to complete each entry of the Activity Logs immediately following the activity to insure the accuracy of the data collection.

Two additional sources of data were the state Client Process Monitoring System (CPMS) and Medicaid Management Information System (MMIS). These systems are designed to track information on children's mental health services, including diagnosis, dates of services, types of services received, and the cost of those services. While a substantial amount of data were potentially available from these systems, their usefulness was severely limited due to lag time and the way that the data are maintained and reported. Consequently, no data from these sources are reported here.

Table 3
Constructs and Measurement Methods

Construct/Category	Instrument	Source	Data Collection Point: Initial	Follow-Up
Child Characteristics:				
Date of Birth	Interview	Caregiver	X	
Gender	Interview	Caregiver	X	
Race	Interview	Caregiver	X	
Past mental health services	Interview	Caregiver	X	
Caregiver Characteristics:				
Relationship to child	Interview	Caregiver	X	
Marital status	Interview	Caregiver	X	
Educational level	Interview	Caregiver	X	
Caregiving burden	Interview	Caregiver	X	X
Help with caregiving	Interview	Caregiver	X	X
Past mental health services	Interview	Caregiver	X	
Family Characteristics:				
Annual Household income	Interview	Caregiver	X	
Financial resources	Interview	Caregiver	X	
Distance to mental health office	Interview	Caregiver	X	X
City/Town population[1]	Interview	Caregiver	X	X
Population Type (urban/rural)	Interview	Caregiver		X
Child Functioning:				
Total Behavior Problems	CBCL[2]	Caregiver	X	X
Internalizing Behavior Problems	CBCL	Caregiver	X	X
Externalizing Behavior Problems	CBCL	Caregiver	X	X
Family Functioning:				
Coping strategies	F-COPES[3]	Caregiver	X	X
Past and current well-being	Interview	Caregiver		X
Family Empowerment	FES[4]	Caregiver	X	X
Barriers To Services:				
Expected Barriers	Interview	Caregiver	X	
Current Barriers	Interview	Caregiver		X
	FBS[5]	Caregiver		X
	RIIFF[6]	Family Assoc.	End of FA Services	
Mental Health Services:				
Type & frequency of services	Interview	Caregiver		X
Family Associate Services:				
Services Provided	Activity Log	Family Assoc.	End of FA Services	
	FBS	Caregiver		X
	RIIFF	Family Assoc.	End of FA Services	
Assessment of services	Interview	Caregiver		X
Cash Fund Expenditures	Activity Log	Family Assoc.	End of FA Services	

[1] 1990 Oregon Population Census
[2] Child Behavior Checklist (Achenbach, 1991)
[3] Family Crisis Oriented Personal Evaluation Scales (McCubbin, Olson, & Larsen, 1981)
[4] Family Empowerment Scale (Koren, DeChillo, & Friesen, 1992)
[5] Family Barriers Scale
[6] Ratings of Important Issues for Families

CHAPTER IV
RESULTS

This chapter presents the results from the research conducted under the Family Connections Project. In the first part of this chapter, the comparability of the two research groups, intervention and comparison, are discussed to provide a basis for the results that come after. Analysis related to each of the research questions follows.

Comparability of Groups

It is important to carefully examine the characteristics of the intervention and comparison groups to see if there were any major differences. Group comparisons (t tests, chi square analyses) revealed that the families included in the intervention (n = 96) and comparison (n = 143) groups were not significantly different on any of the family characteristics listed in Table 2 (Chapter III).

Additional group comparisons on the three initial CBCL broadband scores and the six initial F-COPES scores also showed no significant differences. Only the FES family score measured at the initial interview resulted in a significant difference between groups ($p < .05$). On this indicator of the families' feeling of empowerment regarding their family situation, the intervention group reported a lower level of family empowerment. The other FES scores, service system and community/political empowerment, were not significantly different for the two groups. The data from the analyses of the CBCL, F-COPES, and FES scores are presented in Table 4.

Table 4
Group Scores on CBCL, F-COPES, and FES

	Intervention		Comparison		
Score	*M*	*SD*	*M*	*SD*	*t*
CBCL					
Internal	63.0	12.9	62.7	11.1	.24
External	65.1	12.1	63.9	11.5	.76
Total	65.5	11.7	65.5	10.1	.03
F-COPES					
Social Support	24.4	6.6	25.4	5.9	1.29
Neighbor Support	7.4	3.2	7.3	2.7	.15
Reframing	29.7	5.2	30.1	5.0	.59
Spirituality	13.0	4.1	12.9	4.7	.06
Mobilization	12.4	5.5	13.0	1.8	1.79
Passivity	15.1	3.3	15.4	2.9	.80
FES					
Family	45.6	7.1	47.6	6.4	2.29*
System	49.6	5.8	49.4	6.0	.16
Community	27.8	7.3	28.9	7.3	1.08

*$p < .05$

Intervention Outcomes

Impact on Service Participation. Data regarding the impact of the Family Associate intervention on mental health service participation were examined using chi-square analyses (see Table 5). The intervention group was significantly more likely to initiate children's mental health services, $\chi^2(1, n = 239) = 6.94$, $p < .01$. The associated Yule's Q statistic was .51, suggesting a moderately strong relationship between the intervention and initiation of services (Bohrnstedt & Knoke, 1994). The groups did not, however, differ in attendance $\chi^2(1, n = 204) = .63$, $p = .43$, with roughly one-third of both groups missing no appointments, nor did they differ in discontinuing mental health services prematurely $\chi^2(1, n = 203) = .002$, $p = .96$, with less than one-quarter of both groups dropping out of services. It is important to note that appointment attendance was treated as a dichotomous variable (missed no appointments was scored as 0, missed any appointments was scored as 1) because the time period was short and a variable based on proportion of appointments would be misleading (e.g., 50% attendance could reflect missing 5 of 10 scheduled appointments or 1 of 2 scheduled appointments).

Table 5
Impact of Family Associate Services on Mental Health Service Participation

	Intervention Group		Comparison Group	
Variable	n	%	n	%
Initiated Services	89	93	115	80**
Missed Any Appointments (i.e., attendance)	59	66	70	61
Discontinued Services	24	27	31	27

**p<.01.

To investigate the possibility that initial sample characteristics might have accounted for the significant difference in service initiation rather than the intervention, a hierarchical logistic regression was performed. Six variables representing sample characteristics were entered into the equation first, followed by a dichotomous variable representing the intervention/comparison distinction. The sample characteristics variables were respondent's years of education, child's race (White or other), annual household income, miles to mental health services, CBCL total problem behavior score, and FES family empowerment score. These six variables were chosen on the basis of their importance in previous studies or, in one instance (FES family empowerment score), on a significant difference between the intervention and comparison groups at the initial interview. Although the model chi-square for the combination of family characteristics was significant, $\chi^2(6, n = 239) = 12.74$, $p < .05$, the addition of the intervention/ comparison variable significantly improved the model $\chi^2 (1, n = 239) =$

6.28, $p < .05$. The R statistic associated with this variable was .14 ($p < .05$); whereas only one other R statistic, that for respondent education, was significant ($R = .13$, $p < .05$). This pattern of findings suggested that receiving Family Associate services was significantly associated with service initiation after the effects of various sample characteristics had been taken into account and that a higher level of respondent education was also associated with service initiation.

Barriers to Service Involvement. One way to understand these outcomes is to look at the barriers identified at each level of potential service involvement. During the follow-up interview, if a child was identified as not initiating services, as missing any appointments, or as prematurely ending services, the caregivers were asked to indicate which of a list of barriers interfered with their ability to participate in mental health services. It is important to note that the number of families who failed to initiate services ($n = 7$ intervention, $n = 28$ comparison) and discontinued services prematurely ($n = 25$ intervention, $n = 32$ comparison) are small. As a result the number of respondents listed for each barrier is quite small. The most frequently reported barriers (at least 20% of the respondents) for the two groups at each of the three service participation points are presented in Table 6 (complete lists of all barriers are found in Appendix K).

Table 6
Barriers to Mental Health Service Initiation, Attendance, and Continuance

Group	Barrier (rank ordered)	n	%
	Barriers to Initiating Mental Health Services		
Intervention (n = 7)	Child Care Problems	4	57
	Time Conflict	3	43
	Transportation Problems	2	29
	Child Refused Treatment	2	29
	Did Not Think MHS Would Help	2	29
	Confused About Next Step	2	29
	Child Did Not Need MHS	2	29
	Would Not Meet Cultural Needs	2	29
	Family Illness/Problems	2	29
Comparison (n = 28)	Time Conflict	12	43
	Confused About Next Step	12	43
	Child Did Not Need MHS	9	32
	Child Care Problems	4	29
	Transportation Problems	6	21
	Child Refused Treatment	6	21
	Barriers to Attending Mental Health Appointments		
Intervention (n = 59)	Time Conflict	28	48
	Transportation Problems	24	41
	Child Refused Treatment	12	20
Comparison (n = 70)	Time Conflict	31	44
	Family Illness	20	29
	Barriers to Continuing Mental Health Services		
Intervention (n = 59)	Disliked Therapist/Program	7	35
	Did Not Think MHS Were Helping	7	35
	Disagreed with Diagnosis/Treatment	7	35
	Time Conflict	6	30
	Child Refused Treatment	6	30
	Transportation Problems	6	30
	Family Moved	6	30
	Were Not Meeting Cultural Needs	5	25
	Family Problems	4	20
Comparison (n = 70)	Time Conflict	6	29
	Did Not Think MHS Were Helping	6	29
	Disliked Therapist/Program	4	19

Note: Barriers identified by 20% or more of the families in each group are listed. Complete listings of the barriers are located in Appendix K. More than one barrier could be identified by each respondent.

The barrier represented by time conflict figures prominently at each of the three mental health service participation points. Although this barrier may mean something different to each family, clearly, other activities and commitments are in competition with the mental health appointments. In many cases, the other commitments may be appropriately assessed as more important. Problems with obtaining child care are also mentioned frequently, especially with regard to initiating mental health services. This barrier seems to be overwhelming enough to keep families from starting services, but once started, it does not seem to play a major role in either missing appointments or continuing in services. Being confused about the next step in the process seemed to trouble many families, again with special regard to getting started in mental health services. This barrier was much more pronounced for the comparison families, probably because it was addressed by the Family Associates for most of the intervention families.

Another barrier worthy of mention is the part played by the child's refusal to attend mental health appointments. This barrier is mentioned with reference to all three service participation points, yet it seems to be more of a problem for intervention than for comparison families. Although the exact reason for this difference is unclear, this barrier could be addressed by mental health providers or by persons in a Family Associate role through providing information about mental health services aimed at children and adolescents or by providing parents with information about managing this behavior.

Family Well-Being. Chi-square analyses were performed on the family well-being data to examine differences that occurred over time. The sample used for these analyses was limited to those families who initiated services to control for the effect of participating in treatment.

Two time intervals were used in the analysis. The first interval spanned the period between the initial interview and either the termination of Family Associate services (for the intervention group) or two months after the initial interview (for the comparison group). The second interval spanned the period from the end of the first interval to the follow-up interview. Since the data on well-being had been collected in a manner that graphically represented change, the analysis was based on an examination of ordinal differences between the different time intervals. Families who indicated that their situations showed a positive change ("got better") were given a score of 1, families who indicated that their situation stayed the same were given a score of 0, and families who indicated that their situations showed a negative change ("got worse") were given a score of -1. A crosstabulation of these scores by group is presented in Table 7. These data demonstrate that the intervention families differed significantly in their reports of positive change during the period when they received Family Associate services χ^2 (2, n = 203) = .71 (p = .70).

Table 7
Change in Family Well-Being By Group

Change Score	Intervention Group[a]		Comparison Group[b]	
	n	%	n	%
	Time Interval I[c]			
Got Better (1)	73	83	67	58
Stayed the Same (0)	7	8	32	28
Got Worse (-1)	8	9	16	14
	Time Interval II[d]			
Got Better (1)	57	65	74	64
Stayed the Same (0)	19	22	29	25
Got Worse (-1)	12	14	12	10

[a]n = 88. [b]n = 115. [c]Time Interval I spanned from the initial interview to either the termination of Family Associate services (for the intervention group) or two months later (for the comparison group). [d]Time Interval II spanned from the two-month point to the follow-up interview.

Levels of Empowerment. To examine levels of empowerment at follow-up, analyses of covariance (ANCOVA) were conducted on each of the three empowerment scores, with pretest scores serving as covariates. The sample in these analyses was limited to those families who initiated services. Tests for heterogeneous regression slopes were nonsignificant, suggesting that the use of common slopes here was appropriate. Because ANCOVA procedures applied to quasi-experimental data potentially yield biased results due to covariate measurement error (Huitema, 1980; Pedhazur, 1982; Pedhazur & Schmelkin, 1991), parallel analyses were also performed with true-score corrected covariates (Huitema, 1980). Separate analyses were based on covariates corrected with alpha coefficients and with pooled within-group test-retest coefficients. The results from these analyses indicated modest but significant differences in both family and service system empowerment between the intervention and comparison groups. For family empowerment, adjusted post test means based on the standard ANCOVA were 47.5 and 46.4, $F(1, 200) = 7.99$, $p < .01$, $eta^2 = .03$, for intervention and comparison groups, respectively. For service system empowerment, adjusted post test means based on the standard ANCOVA were 50.9 and 49.3, $F(1, 200) = 4.43$, $p < .05$, $eta^2 = .02$, for the intervention and comparison groups, respectively. No significant differences were found with respect to community/political empowerment, with adjusted post test means of 29.4 and 28.9, for the intervention and comparison groups, respectively.

Lane County Group Comparisons and Outcomes. The inclusion of a comparison group in Lane County allowed analyses to be performed on two samples of families who sought services within the same county mental health system. Prior to evaluating the impact of the intervention, the two groups were compared (t-tests, chi square analyses) on all of the family characteristics listed in Table 2, as well as initial interview CBCL, F-COPES, and FES scores. These comparisons revealed that the families included in the Lane County intervention (n = 50) and comparison (n = 37) groups were not significantly different.

The results of the analyses regarding the impact of the Family Associate intervention on children's mental health service initiation, attendance, and continuance in Lane County intervention (n = 50) and comparison (n = 37) groups are presented in Table 8. None of the comparisons were significant at the .05 level; however, the analyses revealed trends similar to those found within the total research sample. The group differences for service attendance and continuance were negligible for the Lane County samples, yet the group differences for service initiation were significant at the p = .07 level. The power of this analysis was reduced by the smaller sample sizes in the Lane County comparison which likely contributed to the reduced significance level. Additionally, the eta statistics for the two analyses were similar (eta^2 = .17 for the project analysis, eta^2 = .19 for the Lane County analysis), indicating that the strength of association between the independent and dependent variables was similar in the two sets of data. Considering all of these results, it can be concluded that the intervention group was more likely to initiate mental health services than the comparison group in Lane County.

Table 8
Impact of Family Associate Services on Mental Health Services Participation in Lane County

	Intervention Group[a]		Comparison Group[b]	
Variable	n	%	n	%
Initiated Service	45	90	28	76
Missed Any Appointments (i.e., attendance)	29	64	18	64
Discontinued Services	12	28	6	23

[a]n = 50. [b]n = 37.

Family Associate Summary

Barriers to Children's Mental Health Services. One of the goals of this research was to describe the barriers experienced by the intervention families and those addressed by the Family Associate services. As illustrated in Table 9, data from the Family Barriers Scale (FBS) revealed that the barriers most commonly experienced by the intervention families were: (a) lack of respite care (55%), (b) transportation problems (51%), (c) lack of recreational opportunities (48%), (d) lack of emotional support (48%), and (e) difficulty paying for utilities (41%). Of all the barriers, the Family Associates most frequently addressed transportation problems, the lack of information about mental health services, the lack of emotional support, and the lack of recreational opportunities. Notably, the Family Associate services were able to meet the need of the families in only one instance: lack of information about mental health services.

Table 9
Barriers Experienced and Barriers Addressed by Family Associate Services: Family Member Report

	Percentage of Intervention Families			
	Experienced Barrier[a]		Received FA Services	
Barrier	n	%	n	%
Respite Care	53	55	10	10
Transportation Problems	49	51	40	42
Recreational Opportunities	46	48	29	30
Emotional Support[b]	45	48	36	38
Paying Utilities	39	41	8	8
Child Care[b]	37	39	10	11
Daily Living Tasks[b]	35	37	4	4
Information About EBD	33	34	13	14
Information About MHS	33	34	37	39
Clothing	31	32	10	10
Food	25	26	1	1
Contact with Other Parents[b,c]	24	25	2	2
Obtaining Benefits	17	18	3	3

Note: n = 96 (except where noted differently). Barriers were rank ordered by proportion of families experiencing each barrier. Barriers have been abbreviated to fit into the table and should be interpreted as difficulty with the areas listed (e.g., *lack of* respite care). FA = Family Associate. EBD = Emotional and Behavioral Disorders. MHS = Mental Health Services.
[a]Based on combining the ratings of *slightly important*, *moderately important*, and *very important*. [b]n = 95.
[c]Contact with other parents who have children in mental health services.

Similar data regarding barriers to mental health services and the accompanying Family Associate services were collected from the Family Associates using the Ratings of Important Issues for Families (RIIFF). These data are presented in Table 10. From the Family Associates' point of view, the barriers most frequently experienced by the intervention families were (a) lack of emotional support (86%), (b) lack of information about mental health services (68%), (c) transportation problems (53%), (d) lack of information about emotional and behavioral disorders (EBD) in children (51%), and (e) lack of recreational opportunities (46%). Comparing the reports of the family members (FBS) and Family Associates (RIIFF), family members reported that 9 of the 13 barriers occurred more frequently than did the Family Associates. These were (a) problems in paying for utilities, (b) not enough food, (c) problems with daily living tasks, (d) lack of respite care, (e) lack of contact with other parents, (f) lack of childcare, (g) not enough clothing, (h) difficulty obtaining benefits, and (I) lack of recreational opportunities. In contrast, the Family Associates perceived that four of the barriers occurred more frequently than did the families: (a) lack of emotional support, (b) lack of information about mental health services, (c) lack of information about EBD, and (d) transportation problems. These differences in perception may be due in part to the training given the Family Associates and the types of resources they had available to offer families.

Table 10
Barriers Experienced and Barriers Addressed by Family Associate Services: Family Associate Report

	Percentage of Intervention Families			
	Experienced Barrier[a]		Received FA Services	
Barrier	n	%	n	%
Emotional Support	82	86	78	82
Information About MHS	65	68	54	57
Transportation Problems	50	53	48	51
Information About EBD	48	51	35	37
Recreational Opportunities[b]	43	46	36	38
Clothing[b]	24	26	20	21
Child Care	24	25	15	16
Respite Care	22	23	13	14
Daily Living Tasks	13	14	6	6
Obtaining Benefits	12	13	5	5
Paying Utilities[b]	10	11	8	9
Contact with Other Parents[c]	9	10	8	8
Food[d]	1	1	1	0

Note: n = 95 (except where noted differently). Barriers were rank ordered by proportion of families experiencing each barrier. Barriers have been abbreviated to fit into the table and should be interpreted as difficulty with the areas listed (e.g., *lack of* respite care). FA = Family Associate. EBD = Emotional and Behavioral Disorders. MHS = Mental Health Services.
[a]Based on combining the ratings of *slightly important*, *moderately important*, and *very important*. [b]n = 94. [c]Contact with other parents who have children in mental health services. [d]n = 93.

Evaluation of the Family Associate Services. In general, the Family Associate services were rated highly by the intervention families. The FBS included an opportunity for families to rate their need for Family Associate Services. As can be seen in Table 11, the majority of families (91%) reported a moderate to high need for the services. The Family Associates, however, rated the need for their services somewhat differently. Results from a similar item on the RIIFF revealed that the Family Associates perceived only 71% of the families as having a moderate to high need for Family Associate services (see Table 11). A more detailed look at these data showed that although the two items are significantly correlated ($r = .24$, $p < .05$), the ratings from the two sources (respondents and Family Associates) are significantly different ($t = 4.68$, $p < .001$). This difference could be accounted for by respondents' appreciation for the attention to their needs and the Family Associates' avoidance of over-valuing their services.

Table 11
Reported Need for Family Associate Services

	Respondent Report[a]		FA Report[b]	
Rating of Need	n	%	n	%
High	61	64	37	39
Moderate	26	27	30	32
Slight	8	8	23	25
None	1	1	4	4

Note: $r = .24$, $p < .05$, and $t = 4.68$, $p < .001$, for respondent and FA ratings of need.
FA = Family Associate. [a]n = 96. [b]n = 94.

The follow-up interview included additional items that measured the intervention families' assessment of the Family Associate services. The majority of families were *very satisfied* with their relationship with the Family Associate (86%) and reported that the Family Associate was *very helpful* with initiating mental health services for their children (77%). Furthermore, respondents were asked to identify the most helpful thing the Family Associate did for them. These responses were coded into three general categories, with some respondents commenting on more than one category. *Practical assistance* was defined as paying for, finding, developing, and/or coordinating services (i.e., the concrete assistance provided to break down barriers), and was identified by 63% of the families. *Supportive understanding* was coded for comments indicating that the Family Associate conveyed a caring attitude, took a parent's opinions and concerns seriously, treated the family as a key resource, recognized a parent's limitations and competing responsibilities, and included the parent in the decision-making process. *Supportive understanding* was noted by 45% of the families. *Information sharing* was defined as informing the parent about service options, reasons for certain requirements

within the service delivery system, mechanisms for parents to be involved in service planning, and available community services and resources, and was identified by 23% of the families. To provide a qualitative flavor to this data, a selection of the responses is reproduced in Table 12.

Table 12
Examples of Most Helpful Family Associate Services

Practical Assistance:
"She helped me get cab rides until we bought the car and then she helped buy the car."
"She called [service provider] and got them going. I had been waiting about two months."
"Gave us $100 for rent in July. I don't know what we would have done without that."

Supportive Understanding:
"She was real; spent time talking on a person-to-person level."
"She sincerely cared about me as a person."
"Realized I've got strength. Gave me encouragement that I can do it. She talked to me."
"She made me feel like it's OK to worry about being a single parent. That it is a hard job and if there are rough times that doesn't mean that you're a failure or a bad parent."
"Helped me to understand that I wasn't the only one with a problem child and that it could be overcome."
"She helped me feel more positive about my role as a grandparent and Caregiver. She bolstered me up. She made me feel good about myself. I felt that I could do anything when she was around."

Information Sharing:
"She explained the services well and basically broke down my hesitancy to use services."
"She gave me information about resources I didn't know about."
"She answered our questions about counseling services available and resources available with a medical card [i.e., Medicaid]. She made us aware of our choices and helped us ask important questions regarding services."
"She gave information in a clear way and got some extra things for us that I didn't know about."
"Just explained the resources I had -- not to just sit around and wait but what I could do."

Flexible Fund Support. Data from the Family Associate Activity Log revealed that the majority of intervention families received flexible fund support (77%), with an average of $175 spent for each family. The majority of families reported that receiving the money made initiating mental health services easier. A detailed account of the expenditures is presented in Table 7. Private transportation (e.g., car repairs, gas, tires, and insurance) was the expense category for which the Family Associates most frequently reported using the family support cash fund to reduce families' barriers to service participation. The highest average amount spent per expenditure was made in the daily living needs category (e.g., heating costs, telephone installation, laundromat expenses). The category of recreation/entertainment was unexpectedly prominent in this data. The Family Associates found that this resource provided parents, oftentimes exhausted from taking care of a child(ren) with special needs, a much-needed break by offering the child(ren) recreational opportunities (e.g., martial arts, scouting, swimming) outside of the home. This recreation/entertainment was often a substitute for more traditional child/respite care services that were difficult to locate.

Table 13
Family Support Cash Fund Expenditures

Expenditure Category	Number of Families[a]	Number of Expenditures[b]	Average $ Per Expenditure
Transportation-Private	38	57	$89
Recreation/Entertainment	29	37	$69
Daily Living Needs	19	22	$97
Transportation-Public	9	15	$33
Personal Effects	9	13	$78
Respite/Child Care	6	7	$56

[a]n = 74. [b]n = 151.

Other Findings Regarding MHS

The findings in this study were enhanced by some exploration of topics relevant to, but not directly dictated by, the research questions. For the most part, these diversions were into topics related to the shape and functioning of the service delivery system and to the families' reactions to the mental health services they received. These additional findings are discussed in the following section. This section also contains a discussion of data collected regarding the topic of rurality and the isolation felt by families who live in rural areas. Because so little conclusive information exists in the literature regarding this topic, a special analysis was conducted to inform our research.

EPSDT Referral Process. Data were gathered from all families (n=239) during the initial interview to describe the EPSDT referral process (e.g., the EPSDT screening, called the Medicheck) and the respondents' experiences with this process (see Table 14). Caregivers were the most common initiators of this process, followed by staff in mental health (including the Family Associate) or education systems. Additionally, the majority of medichecks were performed by private physicians. Those children who had no medicheck at the time a request for mental health services was made were instructed to have one done as soon as possible. These data indicate that although EPSDT was designed to be a physician-based, preventive program to detect disabling conditions in children, people outside of the medical community were initiating the referral process for most children. Furthermore, the public medical sector was not responsible for performing the majority of medichecks, suggesting that families on Medicaid in Oregon are not necessarily utilizers of public health services.

Table 14
Characteristics of the EPSDT Medicheck

Characteristic	n	%
Person Who Suggested a Medicheck		
Parent/Caregiver	89	38.5%
Mental Health Worker	57	25.0%
School Teacher, Counselor, Nurse	37	16.0%
Doctor, Public Health Nurse	16	7.0%
AFS[a] Worker	16	7.0%
Children's Services Worker	6	2.5%
Other	9	4.0%
Don't Know	1	.4%
Person Who Did the Medicheck		
Private Physician	152	63.5%
Public Health	31	13.0%
School Nurse	33	14.0%
No Medicheck Done	23	9.5%

Note. AFS = Adult and Family Services (i.e., welfare).

Data were also gathered regarding the respondents' evaluation of the referral process (see Table 15). The majority of respondents reported that they were satisfied or very satisfied with how they were treated during the referral process (75%) and that the referral process lasted two months or less (70%). The respondents' opinions regarding the speed of the process varied, with approximately one-quarter of the

respondents endorsing each of the choices. Although the process was rated as somewhat easy or very easy by 58% of the respondents, nearly one-third (32%) rated the process as somewhat difficult or very difficult. It is important to note that only 17% of the respondents reported receiving a copy of the referral form that not only provided the Caregiver with documentation that a referral had been made, but also indicated the agency to which the child had been referred. Sixty-eight percent of the respondents reported being contacted by the mental health agency that received the referral in either the form of a telephone call (24%) or a letter (15%) or both (29%). An additional 17% of the respondents initiated the contact (by telephone) with the mental health program. This left only 15% of the sample who had no contact with mental health after the EPSDT referral was made.

Table 15
Caregiver Experiences With The EPSDT Medicheck Process

Experience	n	%	Experience	n	%
Satisfaction With How Treated			**Duration Of The Referral Process**		
Very Satisfied	103	43.0	< 1 month	84	35.5
Satisfied	76	32.0	1 - 2 months	82	34.5
Mixed Feelings	52	22.0	3 - 4 months	44	18.5
Dissatisfied	4	1.5	5 - 11 months	24	10.0
Very Dissatisfied	3	1.5	≥ 1 year	3	1.0
			Don't know	2	.5
Speed Of The Referral Process			**Ease Of The Referral Process**		
Way Too Slow	58	24.5	Very Easy	93	39.0
Kinda Slow, But OK	55	23.0	Somewhat Easy	46	19.0
Just About Right	57	24.0	Just Fine	24	10.0
Faster Than I Expected	68	28.5	Somewhat Difficult	51	22.0
			Very Difficult	24	10.0

Barriers Experienced By Comparison Families. Another area of interest was the barriers experienced by the comparison families only. These families were not influenced by the Family Associate intervention; therefore, the barriers listed here can be considered more representative of those experienced by the average consumer of children's mental health services in Oregon. The barriers listed by the comparison group on the FBS were rank ordered by proportion of families experiencing each barrier and are presented in Table 16. Looking at just the placement within the rankings, the

barriers of lack of information about mental health services and information about EBD were ranked the highest by the comparison families; whereas, the rankings for these barriers were much lower for the intervention families (8th and 9th, respectively). This provides additional evidence of the importance of the Family Associates' activities. The barrier of lack of respite care was ranked consistently high by both groups.

Table 16
Rank Ordered Barriers Experienced By Comparison Group Families

Barrier	n	%
Information About MH Services	64	46
Information About EBD	62	43
Respite Care	61	43
Contact with Other Parents[a]	58	41
Child Care	57	40
Recreational Opportunities	56	40
Emotional Support	55	39
Transportation Problems	49	34
Paying for Utilities	45	32
Help with Daily Living	42	29
Not Enough Clothing	30	21
Getting Benefits	21	15
Not Enough Food	13	9

Note: n = 143. Barriers have been abbreviated to fit into the table and should be interpreted as difficulty with the areas listed (e.g., *lack of* respite care). Based on combining the ratings of *slightly important, moderately important,* and *very important*. MH = Mental Health EBD = Emotional and Behavioral Disorders.

[a]Contact with other parents who have children in mental health services.

Service System Limitations. In order to capture general reactions of these average consumers (i.e., comparison families) to the process of being referred to and initiating children's mental health services, the follow-up interview included the following final item: "Thinking back to when your child was referred for mental health services, in general, what things could have made the process easier for you?" Of the 139 (97%) caregivers who responded to this item, 69% (n = 96) identified difficulties encountered with the mental health system (including referral sources). The responses fell into five general categories of limitations with the system: (a) limited or confusing information; (b) excessively long or complicated referral or intake process; (c) waiting for an appointment after the intake or first contact with the mental health program; (d) inadequate feedback, responsiveness, or involvement; and (e) limited treatment resources (general or specialized). Each Caregiver's response was coded for any or all of the categories. The proportions of respondents who identified each category of system limitations and examples of comments are listed in Table 17.

Table 17
Comments on the Limitations of the Mental Health Service System

Limited/Confusing Information (n = 39, 41%):

"Brochures or information on children's mental health would have been helpful. A lot of people don't know they have options or that there are agencies out there that can help."

"There needs to be some kind of clearing house for information. Parents don't know where to go or what to do. Just the first step would be helpful."

"Information about how the whole process works so you don't have to stumble through it."

Excessively Long/Complicated Process (n = 39, 41%):

"The referral process was lengthy and complicated -- took several weeks."

"There was a lot of red tape in trying to get him into mental health."

"Knowing the exact steps to take. Took too many phone calls. A clear-cut, exact procedure. ... Oregon Health Sciences University sent us to our doctor. Doctor sent us to the county. County sent brochure. It took three steps!"

"I kept calling and it got frustrating and felt like a run-around. It took from October or November to March to get started. ... It's lost for some parents; the momentum is gone after waiting so long."

Waiting for Appointment (n = 35, 36%):

"Not this long waiting list to get services. Children don't have time limits. When children need help they need help now before they get more out of control. ... It was six weeks of waiting. I had to keep calling and they kept putting me off."

"I requested counseling the first part of February, but didn't see the counselor until May. If it had been a more serious problem where I couldn't control him, I don't think I could have waited."

"Length of time it takes to be seen after the evaluation is way too long!"

Inadequate Feedback, Responsiveness, or Involvement (n = 26, 27%):

"If they see things and notice things they should have let us know what was worthy of concern. They should want us to know about areas of concern so we could have helped [child] make progress."

"They told me they would call me back and I did not get a call. Then I missed it. I called her and she missed my call. Then I gave up."

"If the agency would have returned calls. If they would have listened to me. I had a note from the school saying he should have a male counselor. They assigned him a woman. [Son] would not listen to her at all."

Limited Treatment Resources (n = 12, 13%):

"We need more resources where teenagers feel comfortable. ... There are only three places and those are concerned with drug and alcohol [only]."

"It was difficult to find a therapist, to do play therapy, works with children and sex abuse and to find one who would work with parents and include them."

"I just don't think they have enough personnel. ... Should have more counselors at school so the families don't have to seek an outside agency."

"At first we didn't have a medical card [Medicaid] so we couldn't afford counseling. Having low cost counseling available would help."

Mental Health Services Satisfaction. Looking more generally at satisfaction with mental health services, four items on the follow-up interview were asked of all families (n = 201) who initiated services for the referred child. T tests on these Likert scale items revealed no significant group differences; therefore, data for the total project sample will be presented. The majority of respondents reported being satisfied or very satisfied with the mental health services they received (72%), with how they were treated as parents/caregivers (81%), with the child's therapist (85%), and with their level of involvement in the child's mental health services (76%). A selection of comments associated with each of these items is presented in Table 18.

Table 18
Comments: Mental Health Services Satisfaction (Satisfied or Very Satisfied)

Satisfaction with Mental Health Services:

"He's a totally different kid. He worked through a lot of stuff. He's not wanting to kill my cats."

"Counselor was very good -- got right to the heart of the problem."

"I was surprised he got something out of it."

"The whole family has benefitted. I never realized how much we all really needed it."

Satisfaction with How Treated as a Parent/Caregiver:

"They're always telling me I'm doing great. I need that. I'm treated like a queen."

"He's listened to me, especially when I've gotten real frustrated."

"I feel I was encouraged to participate with her healing. The result was that I felt like my rights were being noticed."

"Everyone was wonderful to me -- kind, patient, and helpful. They listened to me and tried to find options for me. I didn't feel like a number."

Satisfaction with Therapist:

"He's great -- has gone out of his way to develop trust and a relationship with [son]."

"She's really good. She writes me letters to keep in contact; makes sure [son] is okay. She gives him a lot of leeway."

"He's great -- trying real hard to work with us and makes me feel like I'm doing okay. My boys really like him, too."

"Genuinely cared -- they just weren't doing a job. They seemed to enjoy their work and were very professional, but with their emotions in it. They cared about the family."

Satisfaction with Level of Involvement in Child's Mental Health Services:

"Very involved, very satisfied. The therapist included me in sessions at my home."

"Always keeps me up-to-date and lets me know what's going on."

"I was never put off. The counselor would always call and talked to me after her individual session."

Rurality. An additional topic that was examined is the distinction that is often made between rural and urban environments. At first glance, the distinction may seem to be a simple one; however, a broad view of this issue reveals that a variety of geographic, political, social, and psychological factors may be involved. In the literature, there are widely varying perspectives on what it means to be urban or rural, and no single viewpoint or definition is commonly accepted. In this study, the extent to which families lived in urban or rural environments was viewed as a possible influence on their involvement in services; therefore, specific analyses were performed to examine relationships among different rural/urban indicators. Of particular interest was the extent to which different indicators based on distance, population, expectations, and perceptions were similar or different.

The variables concerned with distance were measured in estimated miles (one-way) to particular community destinations. The destinations were the library, hospital, post office, and mental health office. The population variables were published census figures for the city and county in which each family resided. The variables concerned with expectations were based on caregivers' responses during the first interview indicating that services would likely be too distant or that transportation to services would likely be a problem and interfere with their ability to initiate, attend, or continue mental health services. Lastly, an overall self-designation of urban or rural was obtained at the second interview to serve as a general criterion variable with respect to the other variables.

The overall similarity among the distance, population, and expectation variables was examined through factor analysis. The analysis used the principal axis method of factor extraction with squared multiple correlations for communality estimates. Factors with eigenvalues greater than 1.00 were rotated, and an oblique rotation criterion was used to allow factors to correlate. If all variables were highly correlated in a congruent fashion, a single factor would be obtained; however, the analysis revealed three distinct factors, as illustrated in Table 19. The factors tended to reflect the types of variables included in the analysis whereby distance, population, and expectation variables each defined their own factors. However, in two instances, distance variables obtained relatively high loadings on other factors. Distance to the library was inversely related to population, and distance to the mental health office was positively related to expectations of distance or transportation barriers. Since the correlations among factors were small, the results of the factor analysis generally suggested that the urban/rural distinction was multifaceted and that no single indicator could adequately reflect this distinction.

Table 19
Rurality Factors and Factor Loadings

Factor	Variables	Loading
I	Miles to Library	.87
	Miles to Hospital	.65
	Miles to Post Office	.59
	Miles to Mental Health Office	.54
II	County Population	.63
	City Population	.60
	Miles to Library	-.47
III	Expected Barrier: Too Far to Travel	.82
	Expected Barrier: Transportation Problems	.55
	Miles to Mental Health Office	.51

Note. r = -.09 for Factors I and II, r = -.08 for Factors II and III, and r = .18 for Factors I and III.

Why do families consider themselves urban or rural? The issue of self-perception here is a complicated one, since many different circumstances can conceivably influence how families assess their own connectedness or isolation. To gain some insight into this question, stepwise logistic regression was used to examine the relationship of the distance, population, and expectation variables to families' self-designation as urban or rural. Three of the eight variables were retained in the model: city population, miles to the post office, and miles to the hospital. The R statistic for each variable was -.19, .11, and .10, respectively, reflecting the unique relationships between each independent variable and the dependent variable. The overall correct classification rate of the model was 70%. The results of the logistic regression are intuitively understandable in suggesting that city population and distance from essential services influence whether or not families consider themselves as living in a rural environment. Like the factor analysis, these findings also attest to the multiplicity of influences in the urban/rural distinction.

CHAPTER V
DISCUSSION

The aim of the Family Connections Project was to test the effectiveness of using paraprofessionals who provided outreach, information, and support to families initiating children's mental health services following an EPSDT referral. Of particular interest, was the opportunity to examine the effectiveness of "parent-to-parent" support services that are becoming increasingly available throughout the country. Initially developed by advocacy groups for persons with physical disabilities and mental retardation, the family advocacy movement has adopted parent-to-parent contact as a major component of advocacy within children's mental health. The impact of parent-to-parent support on the receiving individual is widely assumed to be positive, but no controlled studies have been available to support this premise. The research conducted through the Family Connections Research and Development Project provides a beginning step toward empirical verification of parent support strategies.

The intervention provided by the Family Associates was effective in helping families initiate mental health services. Families were more likely to make and keep their first appointment at the mental health clinic if they had received supportive services from the Family Associate. The effect of the intervention was moderate, as would be expected with an intervention of relatively low intensity and short duration. When considered with other variables, the effect of the intervention was slightly greater in size than the effect of Caregiver education on service initiation. This finding regarding Caregiver education is consistent with other studies (Garfield, 1986; Wierzbicki & Pekarik, 1993). The finding that the intervention predicted service initiation, while controlling for other demographic characteristics, provides support for the general effectiveness of the intervention.

The Family Associate intervention did not increase the likelihood that families would maintain uninterrupted attendance at clinic appointments. Both intervention and comparison families missed some appointments, and there was minimal difference between the two groups with regard to the pattern or frequency with which appointments were missed. About one-third of both groups missed no appointments; 28% and 18% of the intervention and comparison groups, respectively, missed more than two clinic appointments. It is likely that missing one, or even two, appointments is a common occurrence and does not indicate the presence of a barrier that could interfere with ongoing involvement in mental health treatment. Many families who missed one or two appointments mentioned time conflicts and illness within their family or on the part of the service provider as recurring reasons for missing an appointment. Of great interest for future research is the proportion of families that missed more than two clinic appointments. These families in the intervention group clearly faced barriers to regular attendance that the Family Associate was unable to address. Because the Family Associate intervention was intentionally constructed to cover a short time at the

beginning of treatment, a longer period of intervention may be necessary to address the needs of families who continue to have difficulty attending appointments on a regular basis. In addition, families who were recruited to services by the intervention may experience additional barriers that require longer interventions.

The Family Associate intervention did not increase the likelihood that families would continue in treatment until it was completed, again arguing for a longer intervention. The dropout rate for families in this study was 27% for both groups. This rate is at the low end of the range of dropout rates cited in the literature. For example, Wierzbicki and Pekarik (1993) reported a mean dropout rate of 46.81% over 16 studies, and dropout rates between 25% and 35% are the lowest rates reported in the literature (Forehand et al., 1983; Mannarino et al., 1982; Day & Reznikoff, 1980). However, the dropout rate reported in the present study is even more impressive when considering the generally low income level of these families, a characteristic frequently associated with higher rates of dropping out of treatment (Baekeland & Lundwall, 1975; Garfield, 1986; Wierzbicki & Pekarik, 1993).

Many explanations can be offered for the low dropout rate in this study. First, the definition for dropouts used for this study excluded families that never initiated children's mental health services after a referral was made. Studies that included as dropouts parents who merely contacted an agency but never started services may have inflated the dropout rates previously reported.

Second, the families identified as continuing treatment may have dropped out at a later time after the follow-up interview. This is most likely for the families who started treatment right before the follow-up interview. However, previous researchers have identified that dropout usually occurs in the early stages of treatment, commonly within the first 6 to 12 sessions (Baekeland & Lundwall, 1975; Pekarik, 1991). In this study, approximately two-thirds at the families attended six or more appointments. Taken together, these points suggest that the three to four month time span used in this study allowed plenty of time for dropout to occur for the majority of families.

Third, the sample of caregivers may have been highly motivated to receive mental health services for their children. All of the families were referred for children's mental health services through EPSDT. This process involves having a medical professional make a referral either based on their own observations or at the request of a concerned person (e.g., the parent, a teacher, a child protective services worker). Over one-third of the parents in this sample initiated the EPSDT screening and many others requested help from other professionals who then initiated the screening. Therefore, using EPSDT-referred children for this sample may have selected parents who were committed to getting their children treated for emotional and/or behavioral difficulties.

And fourth, the children's mental health services may have been perceived as quite good and worthwhile receiving. The findings that the majority of parents (72%-85%) were satisfied or very satisfied with the mental health services they received, how they were treated as parents/caregivers, the therapists who provided the treatment, and their level of involvement in the mental health services suggests that the agencies were providing at least adequate, if not exceptional, services to most of the families in this sample. It is also important to note that the services provided through the EPSDT program are free, thereby reducing the financial burden on families.

In addition to helping families get started in mental health services, some conclusions can be drawn about the Family Associate's ability to help families improve their sense of empowerment at both the family and service system levels as well as their sense of family well-being. Families in the intervention group scored significantly higher than families in the comparison group on both family and service system subscales of the FES, although the differences were modest. Similarly, intervention families reported a significantly greater positive change in family well-being during the time they worked with the Family Associate relative to the same time period for comparison families. These findings suggest that paraprofessional outreach may do more than just get families into services: It may also have a positive impact on families' sense of mastery, their ability to cope with difficult situations, and their sense of well-being.

One of the important contributions of this study is the clear explication of the barriers families face while initiating and continuing mental health services. Some of the barriers identified were due to the family's situation, others were related to the organization of the mental health service delivery system. Intervention families most often reported facing barriers with respect to finding respite care, transportation to services, appropriate recreational opportunities, and emotional support, which is similar to findings of previous research on barriers to services participation (Manela et al., 1977; Meisels & Margolis, 1988). The Family Associates were most successful at providing help with transportation, information about emotional and behavioral disabilities, and emotional support. They were less successful in meeting needs for respite care and child care, often because resources were not readily available in the community for these services. In addition, families reported difficulties with circumstances that usually are not associated with access to mental health services but can impede the family's ability to concentrate on supporting their child's treatment. These included difficulty paying for utilities, problems with daily living, lack of sufficient clothing and food. At least one-quarter of the intervention families identified these problems as barriers to their involvement in mental health treatment, yet these were not circumstances that the Family Associates were consistently able to alter. In the future, researchers need to address these areas of difficulty for low-income families and evaluate strategies to reduce their impact on involvement in mental health services.

The perception of the comparison families regarding the barriers that they faced is also instructive. These families were never introduced to the concept of the Family Associate; countering the argument that they might have been "radicalized" by association with the Family Associate. The comparison families endorsed the lack of information about mental health services and information about emotional and behavioral disorders in children as two of the most frequently experienced barriers. Both of these issues were strong components of the Family Associate intervention. The third most frequently endorsed barrier was the lack of respite care -- a finding consistent with the barriers faced by the intervention families and consistent with findings in other studies and programs (Armstrong, Evans, Tannen, & Scudder, 1994; Friesen, 1989; Tarico, Low, Trupin, & Forsyth-Stephens, 1989). As with the intervention families, 20%-45% of the comparison families reported that problems with paying for utilities, activities of daily living, and not having enough clothing affected their ability to obtain mental health services for their children. Addressing these barriers will take a concerted effort and collaborative problem solving by providers from multiple service sectors, not just the mental health system.

Although not a focus of this study, barriers that are erected by the organization and delivery of mental health services were mentioned by some of the families who participated in this study. Primary among these barriers was the problem of obtaining necessary, sufficient, and accurate information about mental health services, particularly regarding what to expect and how to access the services. Some families complained about a lengthy waiting period that seemed to occur after the first intake appointment. Other reported system barriers involved the difficulty of communication between families and providers. Of major importance to these families was the difficulty of getting a phone call returned, apparently due to service providers having limited ability to return phone calls. Communication is also complicated by families commonly being away from home during the day since most AFDC recipients now work or go to school, and by some families not having phones at home and needing to rely on messages through friends or relatives. Although these system-related barriers were not the focus of the Family Associates' activities nor this research project, the fact that they were spontaneously mentioned by two-thirds of the comparison families suggests that they must be addressed in order to improve the provision of children's mental health services.

Looking at the qualitative evaluation of the Family Associate services, most participants in the intervention group liked the Family Associate services that they received and perceived them to be beneficial. The findings that 91% of the families reported a moderate to high need for the Family Associate services and 77% felt that the Family Associate had been very helpful in getting them started in mental health services provide further support for the positive influence this intervention had on these families. Interestingly, the Family Associates reported that only 71% of the families needed their services moderately or very much. Although this is still a large proportion

of the families, the significant difference between the parent and Family Associate reports suggests that the two perspectives are fairly different. The parents may be communicating their sincere appreciation for the Family Associate's individual attention to their needs. As noted earlier by the comparison families, navigating within the children's mental health services system can be challenging at best. Being approached by a friendly parent who offers support and guidance as the family initiates mental health services can be quite a relief. Additionally, having a person inquire about barriers to services and unmet needs can draw attention to the family's needs. It is, therefore, not surprising that the majority of parents reported a high need for the Family Associate services. On the other hand, the Family Associates' reports may have been influenced by wanting to avoid over-valuing their services. Additionally, they may have perceived strengths and abilities in the parents to meet their own needs that were not identified by the parents themselves.

A small flexible cash fund was provided for the Family Associates to use as they worked with families; with the understanding that the Family Associate was to consider free or low-cost community resources first before purchasing a product or service. The flexible cash fund was small, with an average of $175 spent on each family that received funding. The Family Associates reported that 23% of the intervention families received no support from this fund because they did not need it, did not want it, or had needs that could be met through free services in the community. The flexible cash fund was spent on a broad variety of services and goods; however, assistance with transportation was the most frequent expenditure. The major strength of the cash fund was its flexibility, allowing the Family Associate to embrace the "whatever it takes" philosophy without concern for state or county restrictions. This flexibility is hard to preserve, but it is a basic requirement for being able to serve the unique needs of low-income families.

Additional lessons learned during this project are related to the design and implementation of the Family Associate intervention. During this demonstration project, the Family Associates were restricted to working with the families from the point of referral until the families had attended their third appointment with a mental health service provider. Initially, concern was expressed that the friendly Family Associate role might interfere with the development of a strong therapeutic relationship between the parent and therapist. In fact, this did not occur, possibly because the intervention time for the Family Associate was too short. Allowing the Family Associate to work longer with some families has been identified as a means of improving outcomes related to continuance in treatment. Another research project that extends the intervention throughout treatment, while at the same time working out relationship issues with the primary therapists, would be warranted.

Issues of training, supervision, and administrative support for the Family Associate were critical to successful implementation of this type of intervention. During

this demonstration project, supervision and administrative support were provided primarily by personnel within the county mental health program at a time when fiscal stress and policy changes made time commitments difficult. Because the Family Associate intervention is a nontraditional outreach role, its overlay on a traditional mental health system was challenging and adjustments on both sides were necessary in order assure a reason able fit. Commitment and support from top administrative officials was an important condition in order for these negotiations to achieve their purpose. Finally, mental health programs that elect to implement similar outreach programs need to insure that families who have cared for, or are currently caring for, a child with a serious emotional disorder are recruited and hired for the Family Associate position. While it is tempting to hire someone who "knows about" the problems of getting mental health services, this intervention is most potent when delivered by an individual who has first-hand knowledge of the barriers and challenges to accessing mental health services for a child.

Given that significant findings emerged with an intervention of relatively narrow focus, there is considerable promise for expanded efforts in this regard. Additional outreach efforts to families, especially when coupled with modifications to the service system, may substantially improve families' chances of accessing mental health services. Most other investigators have examined accessibility from a perspective limited to family demographics and service system issues. This research affirms the importance of adopting a broader view of families' lives when addressing the problems of service accessibility. Future research on access to and dropout from mental health services should explore the importance of barriers related to limited money and the stresses of daily living. In addition, more research needs to be done on the impact of interventions such as the use of Family Associates, but with an expanded focus and over a longer period of time. Our experience with implementing this intervention suggests that it would be even more effective if the Family Associate were free to work with families throughout the process of mental health treatment. On a broader level, there is an ongoing need for research on innovative interventions that approach long-standing accessibility problems in novel and efficient ways. The Family Associate intervention represents a promising effort in this direction.

REFERENCES

Achenbach, T. M. (1991). Manual for the child behavior checklist/4-18 and 1991 profile. Burlington, VT: University of Vermont Department of Psychiatry.

Acosta, F. X. (1980). Self described reasons for premature termination of psychotherapy by Mexican American, Black American and Anglo-American Patients. Psychological Reports, 47, 434-443.

Armstrong, M. I., Evans, M. E., Tannen, N., & Scudder, E. (1994, March). Outcomes of parent and provider-designed systems of care: Research plan and service system design. In C. J. Liberton, K. Kutash, & R. M. Friedman (Eds.), A system of care for children's mental health: Expanding the research base (pp. 179-185). Tampa, FL: Research and Training Center for Children's Mental Health.

Austin, M. J. (1978). Professionals and paraprofessionals. New York: Human Services Press.

Aylward, G. P., Hatcher, R. P., Stripp, B., Gustafson, N. F., & Leavitt, L. A. (1985). Who goes and who stays: Subject loss in a multicenter, longitudinal follow-up study. Developmental and Behavioral Pediatrics, 6(1), 3-8.

Baekeland, F., & Lundwall, L. (1975). Dropping out of treatment: A critical review. Psychological Bulletin, 82, 738-783.

Blouch, R. G. (1982). Rural people. In L. R. Snowden (Ed.), Reaching the underserved (pp. 75-93). Beverly Hills: Sage.

Bohrnstedt, G. W., & Knoke, D. (1994). Statistics for social data analysis (3rd ed.). Itasca, IL: F. E. Peacock.

Budetti, P. P., Butler, J., & McManus, P. (1982). Federal health program reforms: Implications for child health care. Milbank Memorial Fund Quarterly/Health and Society, 60(1), 155-181.

Burns, B. J., Burke, J. D., & Ozarin, L. D. (1983). Linking health and mental health services in rural areas. International Journal of Mental Health, 12(1-2), 130-143.

Carpenter, P. J., Morrow, G. R., Del Gaudio, A. C., & Ritzler, B. A. (1981). Who keeps the first outpatient appointment? American Journal of Psychiatry, 138(1), 102-105.

Carscaddon, D. M., George, M., & Wells, G. (1990). Rural community mental health consumer satisfaction and psychiatric symptoms. Community Mental Health Journal, 26, 309-318.

Chesney, A. P., Brown, K. A., Poe, C. W. & Gary, H. E. (1983). Physician-patient agreement on symptoms as a predictor of retention in outpatient care. Hospital and Community Psychiatry, 34, 737-739.

Clayton, T. (1977). Issues in the delivery of rural mental health services. Hospital and Community Psychiatry, 28, 673-676.

Cohen, J. (1972). The effects of distance on use of outpatient services in a rural mental health center. Hospital and Community Psychiatry, 23, 27-28.

Cowan, S. C. (1979). The rural poor and mental health. Human services in the rural environment, 4(2), 10-18.

Dawson, P., Van Doorninck, W. J., & Robinson, J. L. (1989). Effects of home-based, informal social support on child health. Journal of Developmental and Behavioral Pediatrics, 10(2), 63-67.

Day, L., & Reznikoff, M. (1980). Social class, the treatment process, and parents' and children's expectations about child psychotherapy. Journal of Clinical Child Psychology, 9, 195-198.

Deavers, K. (1992). What is rural? Policy Studies Journal, 20, 184-189.

Durlak, J. A. (1973). Myths concerning the nonprofessional therapist. Professional Psychology, 4, 300-304.

Fiester, A. R., Mahrer, A. R., Giambra, L. M., & Ormiston, D. W. (1974). Shaping a clinic population: The dropout problem reconsidered. Community Mental Health Journal, 10, 173-179.

Finkelhor, D. (1979). Sexually victimized children. New York: Free Press.

Flaskerud, J. H., & Kviz, F. J. (1983). Rural attitudes towards and knowledge of mental illness and treatment resources. Hospital and Community Psychiatry, 34, 229-233.

Flaskerud, J. H., & Kviz, F. J. (1984). Determining the need for mental health services in rural areas. American Journal of Community Psychology, 12, 497-510.

Flax, J. W., Wagenfeld, M. O., Ivens, R. E., & Weiss, R. J. (1979). Mental health and rural America: An overview and annotated bibliography (National Institute of Mental HealthDHWE Publication No. ADM 78-753). Washington, DC: U.S. Government Printing Office.

Forehand, R., Middlebrook, J., Rogers, T., & Steffe, M. (1983). Dropping out of parent training. Behavioral Residential Therapy, 21, 663-668.

Friesen, B. J. (1989). Survey of parents whose children have serious emotional disorders: Report of a national study. Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.

Frith, G. H., & Lindsey, J. D. (1980). Paraprofessional roles in mainstreaming multihandicapped students. Education Unlimited, 2, 17-21.

Gaines, T., & Stedman, J. M. (1981). Factors associated with dropping out of child and family treatment. American Journal of Family Therapy, 9(2), 45-51.

Garfield, S. L. (1986). Research on client variables in psychotherapy. In S. L. Garfield & A. E. Bergin (Eds.), Handbook of psychotherapy and behavior change (pp. 213-256). New York: Wiley.

Garfinkel, B., Hoberman, H., Parsons, J., & Walker, J. (1988). The prevalence of depression and suicide attempts in rural Minnesota youth. In Report of the National Action Commission on the mental health of rural Americans, 1988 (pp. 16). Rosslyn, VA: National Mental Health Association.

Gartner, A. (1981). Paraprofessionals in mental health. In S. S. Robin & M. O. Wagenfeld (Eds.), Paraprofessionals in the human services. New York: Human Science Press.

Gerber, M. M., & Semmel, M. I. (1983). Models for the delivery of technical assistance for rural special education of preschool handicapped children. International Journal of Mental Health, 12(1-2), 144-158.

Goldin, M. (1990). Factors associated with the length of time in treatment at a mental health clinic. Dissertation Abstracts International, 51(4), 1389-A.

Gonzales, L. R., Hays, R. B., Bond, M. A., & Kelly, J. G. (1983). Community mental health. In A. E. K. M. Hersen & A. S. Bellack (Eds.), The clinical psychology handbook. New York: Permagon.

Good, M. I., & Hendrickson, P. A. (1986). A study of postevaluation change in clinician and treatment dropout rates. Hospital and Community Psychiatry, 37, 76-77.

Good, M. I. (1990). Treatment dropout rates. Hospital and Community Psychiatry, 41, 928-929.

Graziano, A. M., & Fink, R. S. (1973). Second-order effects in mental health treatment. Journal of Consulting & Clinical Psychology, 40, 356-64.

Human, J., & Wasem, C. (1991). Rural mental health in America. American Psychologist, 46, 232-239.

Huitema, B. E. (1980). Analysis of covariance and alternatives. New York: Wiley.

Hunt, R. G. (1961). Age, sex and service patterns in a child guidance clinic. Journal of Child Psychology and Psychiatry, 2, 185-192.

Institute of Medicine (1989). Research on children and adolescents with mental, behavioral, and developmental disorders. Washington, D.C.: National Academy Press.

Jones, K. H., & Bender, W. N. (1993). Utilization of paraprofessionals in special education: A review of the literature. Remedial and Special Education, 14(1), 7-14.

Jones, E., & Nickerson, J. M. (1986). A time series study of the effectiveness and costs of EPSDT outreach in Maine. Public Health Reports, 101(1), 68-76.

Karlsruher, A. E. (1974). The non-professional as a psychotherapeutic agent: An empirical investigation of the influence of supervision, expectation and facilitative conditions on his therapeutic effectiveness. Dissertation Abstracts International, 34(12 B, Pt. 1), 6213.

Kelleher, K. J., Taylor, J. L., & Rickert, V. I. (1992). Mental health services for rural children and adolescents. Clinical Psychology Review, 12, 841-852.

Keller, W. J. (1983). Study of selected outcomes of the Early and Periodic Screening, Diagnosis, and Treatment Program in Michigan. Public Health Reports, 98, 110-119.

Keller, P. A., & Murray, J. D. (1982). Rural mental health: An overview of the issues. In P. A. Keller & Murray, J. D. (Eds.), Handbook of rural community mental health (pp. 3-9). New York: Human Sciences Press.

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. Rehabilitation Psychology, 37, 305-321.

Koroloff, N. M., Elliott, D. J., Koren, P. E., & Friesen, B. J. (1994). Connecting low-income families to mental health services: The role of the family associate. Journal of Emotional & Behavioral Disorders, 2, 240-246.

Leaf, P. J., Bruce, M. L., Tischler, G. L., & Holzer, C. E. (1987). The relationship between demographic factors and attitudes toward mental health services. Journal of Community Psychology, 15, 275-284.

Lee, S. H., Gianturco, D. T., & Eisdorfer, C. (1974). Community mental health center accessibility: A survey of the rural poor. Archives of General Psychiatry, 31, 335-339.

Leigh, G., Ogborne, A. C., & Cleland, P. (1984). Factors associated with patient dropout from an outpatient alcoholism treatment service. Journal of Studies on Alcohol, 45, 359-362.

Lochman, J. E., & Brown, M. V. (1980). Evaluation of dropout clients and of perceived usefulness of a parent education program. Journal of Community Psychology, 8, 132-139.

Lorefice, L. S., Borus, J. F., & Keefe, C. (1982). Consumer evaluation of a community mental health service, I: Care delivery patterns. American Journal of Psychiatry, 139,, 1331-1334.

Mannarino, A. P., Michelson, L., Beck, S., & Figueroa, J. (1982). Treatment research in a child psychiatric clinic: Implementation and evaluation issues. Journal of Clinical Child Psychology, 11, 50-55.

Margolis, L. H., & Meisels, S. J. (1987). Barriers to the effectiveness of EPSDT for children with moderate and severe developmental disabilities. American Journal of Orthopsychiatry, 57, 424-430.

Marsh, D. T., Zabarenko, L. M., Stoughton, N. L., & Miller, A. R. (1989). Demographic and clinical variables associated with continuation in treatment at a community mental health center. Journal of Community Psychology, 17, 89-91.

Matthews, A. M. (1988). Variations in the conceptualization and measurement of rurality: Conflicting findings on the elderly widowed. Journal of Rural Studies, 4, 141-150.

McAdoo, W. G., & Roeske, N. A. (1973). A comparison of defectors and continuers in a child guidance clinic. Journal of Consulting and Clinical Psychology, 40(2), 328-334.

McCubbin, H. I., Olson, D. H., & Larsen, A. S. (1991). F-COPES: Family Crisis Oriented Personal Evaluation Scales. In H. I. McCubbin & A. I. Thompson (Eds.), Family assessment inventories for research and practice. Madison, WI: University of Wisconsin-Madison.

McMahon, R. J., Forehand, R., Griest, D. L., & Wells, K. (1981). Who drops out of treatment during parent behavioral training? Behavioral Counseling Quarterly, 1, 79-85.

Meisels, S. J., & Margolis, L. H. (1988). Is the early and periodic screening, diagnosis, and treatment program effective with developmentally disabled children? Pediatrics, 81, 262-271.

Miller, M. K., & Luloff, A. E. (1981). Who is rural? A typological approach to the examination of rurality. Rural Sociology, 46, 608-625.

Munger, R. L. (1988). Expectations of rural and urban parents applying for children's services at community mental health centers. Psychological Reports, 63, 729-730.

Murray, J. D., & Keller, P. A. (1991). Psychology and rural America: Current status and future directions. American Psychologist, 46, 220-231.

Murray, J. E. (1992, July). Spread the word: Medicaid EPSDT changes help home care. Caring Magazine, 54-58.

National Commission on Children (1990). Opening doors for America's children. Washington, D.C.: National Commission on Children.

Offord, D., Boyle, M., & Racine, Y. (1990). Ontario child health study: Children at risk. Ontario, Canada: Queen's printer for Ontario.

Offord, D. R., H, B. M., Szatmari, P., Rae-Grant, N. I., Links, P. S., Cadman, D. T., Byles, J. A., Crawford, J. W., Munroe Blum, H., Byrne, C., Thomas, H., & Woodward, C. A. (1987). Ontario child health study: II. Six-month prevalence of disorder and rates of service utilization. Archives of General Psychiatry, 44, 832-836.

Pedhazur, E. J. (1982). Multiple regression in behavioral research: Explanation and prediction (2nd ed.). Fort Worth, TX: Harcourt Brace College.

Pedhazur, E. J., & Schmelkin, L. P. (1991). Measurement, design, and analysis: An integrated approach. Hillsdale, NJ: Erlbaum.

Pekarik, G. (1985). The effects of employing different termination classification criteria in dropout research. Psychotherapy, 22, 86-91.

Pekarik, G. (1991). Relationship of expected and actual treatment duration for adult and child clients. Journal of Clinical Child Psychology, 20, 121-125.

Pekarik, G., & Stephenson, L. A. (1988). Adult and child client differences in therapy dropout research. Journal of Clinical Child Psychology, 17, 316-321.

Petti, T. A., Benswanger, E. G., & Fialkos, M. J. (1987). The rural child and child psychiatry. In J. D. Noshpitz (Ed.), The basic handbook of child psychiatry (Vol. 5). New York: Basic Books.

Petti, T. A., & Leviton, L. C. (1986). Re-thinking rural mental health services for children and adolescents. Journal of Public Health Policy, 7, 58-77.

Poland, M. L., Giblin, P. T., Waller, J. B., & Hankin, J. (1992). Effects of a home visiting program on prenatal care and birthweight: A case comparison study. Journal of Community Health, 17, 221-229.

Reis, J. S., Pliska, S. R., & Hughes, E. F. X. (1984). A synopsis of federal-state sponsored preventive child health. Journal of Community Health, 9, 222-239.

Rhodes, A. M. (1992). EPSDT: The lawsuit. American Journal of Maternal Child Nursing, 17, 295.

Ross, A. O., & Lacey, H. M. (1961). Characteristics of terminators and remainers in child guidance treatment. Journal of Consulting Psychology, 25, 420-424.

Russell, M. N., Lang, M., & Brett, B. (1987). Reducing dropout rates through improved intake procedures. Social Casework: The Journal of Contemporary Social Work, 68, 421-425.

Scott, R. R., Balch, P., & Flynn, T. C. (1984). Assessing a CMHC's impact: Resident and gatekeeper awareness of center services. Journal of Community Psychology, 12, 61-66.

Sharfstein, S. S., & Taube, C. A. (1982). Reductions in insurance for mental health disorders: Adverse selection, moral hazard, and consumer demand. American Journal of Psychiatry, 139, 1425-30.

Sherman, A. (1992). Falling by the wayside: Children in rural America. Washington, DC: Children's Defense Fund.

Sirles, E. A. (1990). Dropout from intake, diagnostics, and treatment. Community Mental Health Journal, 26, 345-360.

Sledge, W. H., Moras, K., Hartley, D., & Levine, M. (1990). Effect of time-limited psychotherapy on patient dropout rates. American Journal of Psychiatry, 147, 1341-1347.

Small, M. A. (1991). Obstacles and advocacy in children's mental health services: Managing the Medicaid maze. Behavioral Sciences and the Law, 9, 179-188.

Smith, B. J., & Parvin, D. W. (1973). Defining and measuring rurality. Southern Journal of Agricultural Economics, 109-133.

Sobey, F. (1970). The nonprofessional revolution in mental health. New York: Columbia University Press.

Sparer, G., & Johnson, J. (1971). Evaluation of OEO neighborhood health centers. American Journal of Public Health, 61, 931-42.

Stefl, M. E., & Prosperi, D. C. (1985). Barriers to mental health service utilization. Community Mental Health Journal, 21, 167-178.

Stringer, L. A. (1978). Mental health work in children's health centers: Learning from five years' experience. American Journal of Orthopsychiatry, 48, 40-55.

Swett, C., & Noones, J. (1989). Factors associated with premature termination from outpatient treatment. Hospital and Community Psychiatry, 40, 947-951.

Takeuchi, D. T., Leaf, P. J., & Kuo, H. (1988). Ethnic differences in the perception of barriers to help-seeking. Social Psychiatry and Psychiatric Epidemiology, 23, 273-280.

Tarico, V. S., Low, B. P., Trupin, E., & Forsyth-Stephens, A. (1989). Children's mental health services: A parent perspective. Community Mental Health Journal, 25, 313-325.

Temkin-Greener, H. (1986). Medicaid families under managed care: Anticipated behavior. Medical Care, 24(8), 721-732.

Thurston, L. P. (1982, May). Utilizing urban women as peer trainers in behavioral community programs. Paper presented at the Annual Convention of the Associate for Behavior Analysis, Milwaukee, WI.

Tolliver, N. (1990). Early & periodic screening, detection and treatment update. Professional Perspectives, July, 6-7.

Tutin, J. (1987). A multivariate analysis of dropout status by length of stay in a rural community mental health center. Community Mental Health Journal, 23, 40-52.

Viale-Val, G., Rosenthal, R. H., Curtiss, G., & Marohn, R. C. (1984). Dropout from adolescent psychotherapy: A preliminary study. Journal of the American Academy of Child Psychiatry, 23, 562-568.

Wagenfeld, M. O. (1990). Mental health and rural America: A decade review. The Journal of Rural Health, 6, 507-522.

Wierzbicki, M., & Pekarik, G. (1993). A meta-analysis of psychotherapy dropout. Professional Psychology: Research and Practice, 24, 190-195.

Windley, P. G., & Scheidt, R. J. (1983). Service utilization and activity participation among psychologically vulnerable and well elderly in rural small towns. The Gerontologist, 23, 283-287.

Wise, M. J., & Rinn, R. C. (1983). Premature client termination from psychotherapy as a function of continuity of care. Journal of Psychiatric Treatment and Evaluation, 5, 63-65.

APPENDIX A

Family Associate Training Manual
(Selected Pages)

NOTE: This appendix contains selected pages from the Family Associate Training Manual. The Training Manual included its own appendices, which are referenced throughout the following pages. The appendix letters found in the Training Manual do not correspond to the appendix letters of this report.

Only Appendices A and D of the Training Manual are included herein; however, the majority of the materials that were included in Appendices B & C of the Training Manual are found in other appendices of this final report.

FAMILY CONNECTIONS PROJECT

FAMILY ASSOCIATE TRAINING MANUAL

REGIONAL RESEARCH INSTITUTE
PORTLAND STATE UNIVERSITY

and

OREGON MENTAL HEALTH &
DEVELOPMENTAL DISABILITY
SERVICES DIVISION
OFFICE OF MENTAL HEALTH SERVICES

Prepared By:
Debra J. Elliott, M.A.
March 1993

Child and Adolescent Mental Health Service System, Research Demonstration Grant, funded by the National Institute of Mental Health

FAMILY CONNECTIONS PROJECT

KEY PERSONNEL

NANCY KOROLOFF, Ph.D.
Principal Investigator
Regional Research Institute for Human Services
Portland State University
P.O. Box 751*
Portland, OR 97207
(503) 725-4157
FAX: (503) 725-4180

DEBI ELLIOTT, M.A.
Project Manager
Regional Research Institute for Human Services
Portland State University
P.O. Box 751*
Portland, OR 97207
(503) 725-5198
FAX: (503) 725-4180

DIANE MIKKELSON
Support Staff
Regional Research Institute for Human Services
Portland State University
P.O. Box 751*
Portland, OR 97207
(503) 725-4371
FAX: (503) 725-4180

* Mail can also be sent to 1912 SW 6th, Portland, OR 97201.

FAMILY CONNECTIONS PROJECT
INTERVIEWER TRAINING MANUAL

TABLE OF CONTENTS

Portions of this manual were compiled from materials generously provided by Denise Stuntzner-Gibson, M.S.W., Project Manager for the Oregon Partners Project.

SECTION I: PROJECT DESCRIPTION AND BACKGROUND

FAMILY CONNECTIONS PROJECT: EPSDT IMPLEMENTATION AND ACCESS STUDY

The two specific aims of the Family Connections Project are:

1. to study the effectiveness of an *intervention* designed to address the major problems related to service continuance within the children's mental health system in urban and rural areas, including:
   a. a complex service system,
   b. barriers such as lack of transportation or child care and long distance to services, and
   c. possible low motivation to follow through on the part of families whose children's mental health problems are not severe or long-standing;

2. to assess the *implementation* of a model of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) process in Oregon. (Refer to Appendix A for a description of EPSDT and the Oregon Mental health Division's proposal for its implementation.)

The overall goal of the *intervention* is to increase the number of Medicaid-eligible children who receive mental health evaluation and treatment services once they have been identified in the EPSDT screening process as needing them. This will be accomplished by increasing the responsiveness of the system to children and families through the introduction of a *Family Associate* who will assist families in negotiating the service delivery system and overcome barriers to seeking and obtaining evaluation and treatment services. The paraprofessional *Family Associate* is a parent who has experience negotiating within the service delivery system for their child. The services of the *Family Associate* are intended to:

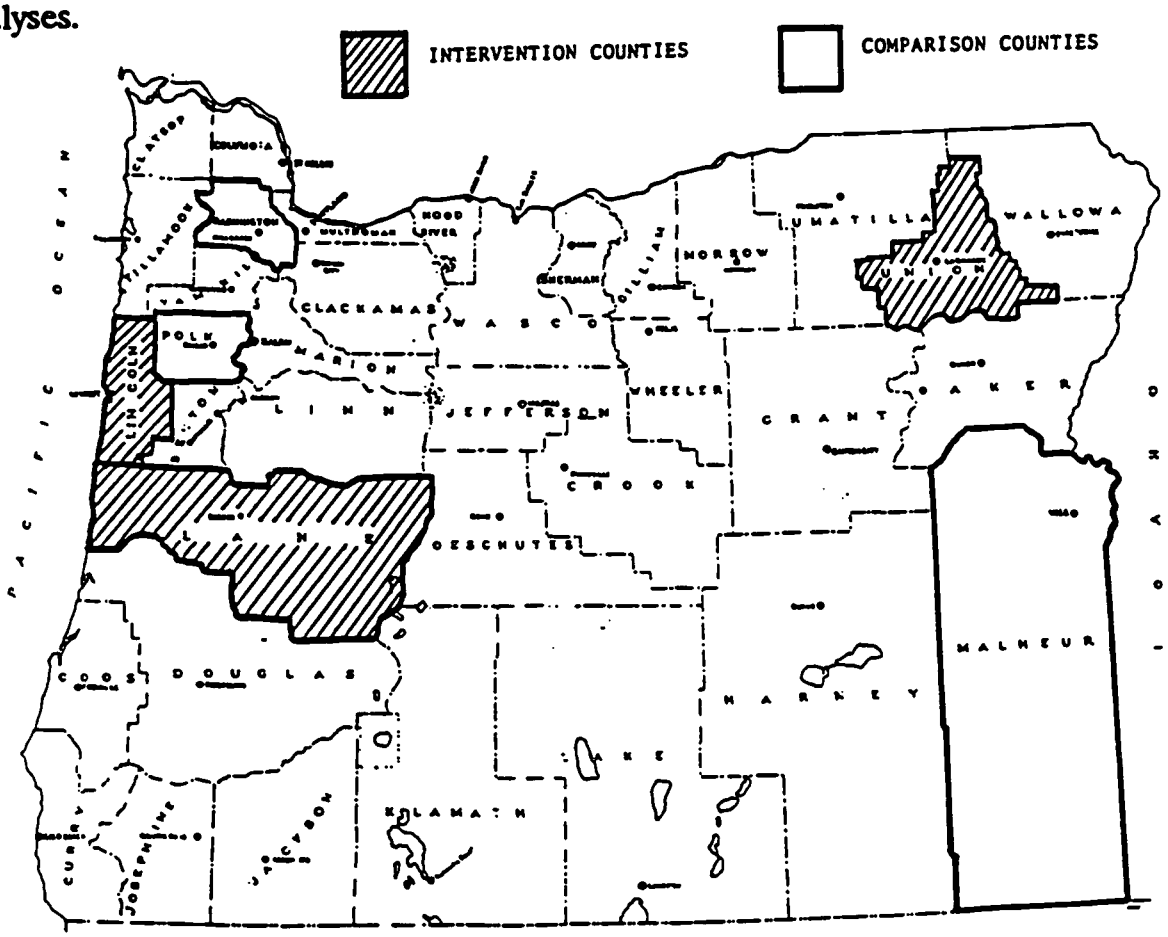
1. emphasize peer assistance rather than professional service,
2. focus on capacity-building, empowerment and competence enhancement,
3. be flexible and responsive to the needs of each individual family, and
4. provide information, social and emotional support, and access to concrete resources.

The research design includes data collection within a set of six counties in Oregon, which were divided into three pairs matched for population density (high, medium, low). Of the 450-500 families who will participate in this study, 200 will be in the counties which receive the *Family Associate intervention* and 200 families will be in the counties selected to serve as non-intervention comparison counties matched for population density. In the largest intervention county, an additional 50-100 families will be selected for a within county comparison group. Parents of children who are [illegible]red for mental health evaluations through EPSDT will be interviewed shortly

after the referral and at a point four months later, regarding their experiences and satisfaction with the services they received. These parents will also be asked to complete a set of standard child and family functioning scales at both data collection points.

The second aim of this project is to address the need for more information about how changes in the service system occur in response to the introduction of a new way of organizing mental health services for low income children and families, with specific emphasis on the issues of system change in rural areas. The overall goal of this portion of the project is to examine the *implementation* of the Oregon EPSDT plan for providing mental health services, which will result in the dissemination of much-needed information to administrators and planners of children's mental health in many states.

Data collection for this second component of the project will involve periodic interviews of County Mental Health Directors, Treatment Planning Coordinators, staff, and service providers, as well as reviews of written material about the county mental health programs. *Implementation* information gathered will include, but not be limited to, the impact of economic, political and social conditions; the approach chosen by the county mental health authority for the delivery of EPSDT services; the extent of interagency collaboration in the delivery of services; the choice of staff and staffing patterns; and the barriers and solutions. An evaluation of the effect of ruralness and increased distance from services will be an additional focus of the analyses.



FAMILY CONNECTIONS PROJECT

HYPOTHESES ABOUT THE EFFECTS OF A FAMILY ASSOCIATE

1. Increased likelihood of the family initiating services

2. Increased sense of family empowerment

3. Increased positive perceptions about the service system

4. Increased optimism regarding the child's prognosis

CONTRASTS

1. Intervention vs. comparison families across counties

2. Intervention vs. comparison families in the largest county

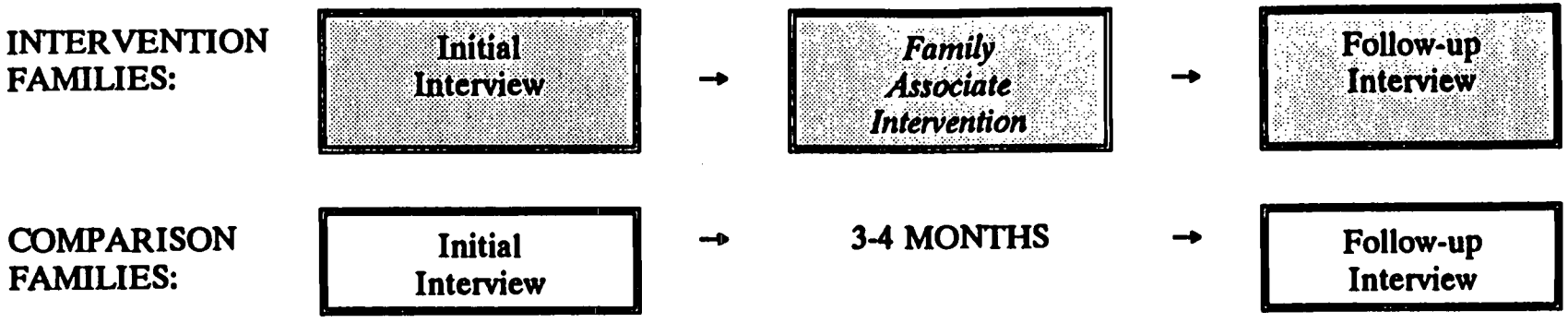
3. High vs. medium vs. sparsely populated counties

FAMILY CONNECTIONS PROJECT: RESEARCH GROUPS

INTERVENTION	HIGH POPULATION:	LANE (n=100) *
	MEDIUM POPULATION:	LINCOLN (n=50)
	LOW POPULATION:	UNION (n=50)
COMPARISON	HIGH POPULATION:	WASHINGTON (n=100)
	MEDIUM POPULATION:	POLK (n=50)
	LOW POPULATION:	MALHEUR (n=50)

* ALSO COMPARED TO A WITHIN-COUNTY SAMPLE OF NON-INTERVENTION FAMILIES

FAMILY CONNECTIONS PROJECT DESIGN AND INSTRUMENTATION



DATA COLLECTED	INSTRUMENT	SOURCE
Child Demographics	Structured Interview	Parent
Family Demographics	Structured Interview	Parent
Child Functioning	Achenbach Child Behavior Checklist	Parent
Family Functioning	F-COPES	Parent
Family Empowerment	Family Empowerment Scale	Parent
Barriers To Services	Ratings of Important Issues For Families	Family Associate
Family Associate Activities	Family Associate Activity Log	Family Associate
Services Received	State CPMS and MMIS Data Bases	Project Manager/MHD
Cost Of Services	State CPMS and MMIS Data Bases	Project Manager/MHD

RESEARCH PROJECT PHASES

PHASE I Pre-Data Collection	FAMILY ASSOCIATE Research Training	PHASE II Research
July 1, 1992- October 4, 1992	*October 5-6, 1992*	*October 7, 1992- December 31, 1992*
<u>FAMILY ASSOCIATES</u>: ▸ Get acquainted with community resources ▸ Work out Family Associate's role ▸ Learn EPSDT process ▸ Clarify referral process ▸ Begin working with a <u>few</u> families ▸ Provide feedback to RRI regarding role and Activity Log	▸ Meeting at RRI ▸ Initial research interview ▸ Use of Activity Log ▸ Tracking and use of cash support fund ▸ Paying families for their participation ▸ Managing the data and other research materials	<u>FAMILY ASSOCIATES</u>: ▸ Enroll families in research project → consistent selection process → informed consent to participate in research ▸ Conduct initial interview with all intervention families ▸ Maintain consistent use of Activity Log ▸ Track cash support fund expenditures <u>RESEARCH INTERVIEWERS</u>: ▸ Research Trainings early November and early January ▸ Conduct follow-up interviews with all intervention families ▸ Conduct initial and follow-up interviews with all comparison families

REGIONAL RESEARCH INSTITUTE MEMBERS: ROLES & ACTIVITIES

	ROLE	ACTIVITIES	CONTACT METHOD
Debi Elliott (725-5198)	Project Manager	Daily operation of project; Supervise Research Interviewers; Implementation Assessment	Call with most questions; Monthly update calls
Diane Mikkelson (725-4371)	Secretary	Travel reimbursement; Event coordination	Call with travel, hotel, food, etc. questions
Nancy Koroloff (725-4157)	Principal Investigator	Overall management of research aspects of project	July '92 county visits; Additional visits and calls as needed
Paul Koren (725-4162)	Research Analyst	Design and methodology; Instrument development; Data analysis	Contacts made as needed
Richard Hunter (725-4161)	Training Director	Training and support of Family Associates	Contacts made as needed
Barbara Friesen (725-4166)	Research & Training Advisor	Research consultation; Training and support of Family Associates	Contacts made as needed

SECTION II: THE ROLE OF THE FAMILY ASSOCIATE

INTRODUCTION AND BACKGROUND

The *Family Associate* role was developed for this research grant based on the belief that a parent paraprofessional can provide support to families who have just had their child referred for mental health services through the EPSDT screening process. The complex children's mental health system can be overwhelming to parents who are already challenged by a child who has emotional and/or behavioral difficulties. Low income families who are referred through EPSDT are doubly challenged by this system complexity due to financial and lifestyle barriers that can interfere with their ability to initiate and continue mental health services for their child. The goal of the *Family Associate* intervention is to assist the parent in breaking down some or all of the barriers that impede their access to the children's mental health system. As both an advocate for the family and a supportive peer for the parent, the *Family Associate* can model skills necessary to maneuver within the mental health system and other community programs. This modeling and collaborative work will have the hypothesized effect of increasing a family's sense of empowerment so they can independently manage the systems in the future.

On the following pages of this section, information is provided to help you better conceptualize the role you will be taking on within your county. As you will notice, some of the materials provide space for you and your supervisor to elaborate on the information provided. This emphasizes the evolving nature of the role. We will provide you with the philosophy which supports the conception of the role and the foundation for the characteristics of the role. However, you and your supervisor will elaborate on that philosophy and foundation to shape the *Family Associate* role into its most beneficial form for your county. We will work with you to create an innovative addition to Children's Mental Health.

ROLE OF THE FAMILY ASSOCIATE

The title of "*Family Associate*" was chosen for the person who will provide assistance to EPSDT-eligible families whose children have been identified as in need of mental health evaluation and/or services during the EPSDT screening process. The *Family Associate* is a paraprofessional-level county employee whose major role is to assist families in negotiating the mental health service delivery system as a part of a research demonstration project.

Job Description for the *Family Associate* Position:

- Provides assistance to families of children eligible for EPSDT-funded mental health services in obtaining those services through providing:
  1. information regarding the evaluation process, the EPSDT process, emotional disorders in children, services authorized through EPSDT, and parents' and childrens' rights and responsibilities;
  2. social and emotional support aimed at decreasing the extent to which the family feels isolated, helpless, and/or intimidated by the service delivery system, with an emphasis on making linkages to other parents and/or to parent support groups; and
  3. access to concrete resources, such as transportation and child care that may be obstacles to seeking and obtaining appropriate mental health services.

- Conducts an initial interview with parents for the purpose of explaining the research project and the services provided by the Family Associate, and completing a short assessment interview.

- Requires the following experience, knowledge, and abilities:
  1. A high school education.
  2. Experience with the mental health system and other child-serving agencies in the county in which the job is located. Preference will be given to parents or other family members of children who have emotional disorders, and who have been recipients of service within the county system.
  3. Knowledge of community resources for children with emotional problems and their families.
  4. Ability to provide families with clear and understandable information about the mental health system and the EPSDT evaluation and planning process.
  5. Ability to conduct an interview for the purpose of giving and gathering information.
  6. Good oral and written communication skills.

7. Ability to work as a member of a project team.
8. Good problem solving skills; ability to work with family members to solve problems and overcome obstacles to seeking and obtaining needed mental health services.

►► Receives supervision from the Treatment Planning Coordinator in the county.

Examples of Principle Duties of the Family Associate:

★★ Makes contact with family to schedule initial interview (by telephone or in person at the family's home, if the family cannot be reached by telephone).

★★ Explains the EPSDT mental health evaluation process, and the assistance available from the Family Associate.

★★ Helps the family identify steps that need to be taken to make an appointment with the Treatment Planning Coordinator for the initial evaluation.

★★ Works with the family to identify any resources (information or concrete assistance) needed to complete any part of the assessment and planning process, I.E., make appointments, travel to interviews or meetings, etc..

★★ When needed, helps to locate community resources, such as child care or transportation, or arranges payment for needed services.

★★ When needed, provides transportation to appointments related to obtaining EPSDT-funded mental health evaluation and/or treatment planning services.

★★ Accompanies families to assessment or planning meetings, when requested by the family.

★★ Conducts initial data collection interview and completes the assessment forms.

★★ Organizes and transmits information to the research team in a timely manner.

★★ Under the supervision of the Treatment Planning Coordinator, follows the protocol for assignment of families to the research demonstration project.

★★ Identifies and communicates problems with the data collection process and/or the Family Associate services to appropriate county or university personnel.

★★ Performs related duties as assigned.

ACTIVITIES TO PREPARE FOR THE FAMILY ASSOCIATE ROLE

Begin Identifying A Range Of Community Resources (Formal & Informal) & Get Acquainted With The People You Need To Know:

1. Transportation
2. Child care
3. Parent support groups
4. Youth support groups
5. Recreational activities
6. Utility and housing opportunities
7. Social services
8.
9.
10.

Familiarize Yourself With The EPSDT Program & How The Process Works In Your County:

1. Medicheck, initial evaluation, comprehensive evaluation, Interagency Services Planning Team, psychiatrist review, Treatment Planning Coordinator, Plan of Care
2. The process from referral to services
3. Family Associate role within the program
4.
5.
6.

Learn More About Emotional Disorders In Children:

1. Review R & T Fact Sheets
2. Look at "Taking Charge: A Handbook for Parents Whose Children Have Emotional Disorders"
3. Look through "Supplemental Readings and Information" notebook
4.
5.
6.

Other Activities Distinctive To Your County:

1.
2.
3.
4.
5.

FAMILY ASSOCIATE ACTIVITIES WORKSHEET

Typical Activities:

1. With Families:
   a. Providing information regarding mental health processes and issues
   b. Helping identify resources (e.g., child care, transportation, etc.)
   c. Interactive problem solving
   d. Helping locate parent-to-parent support
   e. Assisting them in finding their own solutions
   f. Listening to what the family needs and wants
   g. Maintaining an overall goal of independence for the family
   h. Establishing professional/personal boundaries
   i.
   j.
   k.

2. With TPC/Supervisor:
   a. Reviewing status/progress of families
   b. Requesting support/consultation for difficult situations
   c.
   d.
   e.

3. With Agencies:

   a. Learning about services and resources provided (by phone and/or visit)

   b. Introducing self and research project

   c. Making initial contact for services needed by a family, when appropriate

   d. Assisting in coordinating services

   e. Providing agencies with feedback regarding services (positive and constructive)

   f.

   g.

   h.

Try To Avoid:

1. Being seen by the family as a therapist
2. Doing for the family rather than with the family
3. Taking on too many responsibilities
4. Assuming that the family's agenda and your agenda will always be the same
5. Stereotyping either families or providers
6. Getting into power struggles with families or providers
7. Imposing your own ideas
8. Losing your objectivity
9.
10.

FAMILY CASH SUPPORT FUND

In addition to being an advocate for and collaborator with your families, you have access to a Family Cash Support Fund which allows you to supply the families with flexible funding to break down barriers to services. This fund can be used for a anything the family might need that can be identified as related to helping them get their child to mental health services. It is important, however, to first take advantage of all other options within your county to satisfy the needs of these families. These may be free services available in the community, inexpensive items that the family can purchase, or contacts/connections not previously known by the family. The goal is to work with the family to demonstrate how to get their own needs met without creating a dependent relationship between the family and the funds you have available. The funds are most appropriately used when all other resources are depleted and the family has no other mechanism available to satisfy their need(s).

This funding is flexible in that it is up to you to decide what the need(s) of the families are and locate an item or service that best fits the need(s). In the beginning, you will want to discuss the use of this money with your supervisor and the Project Manager to become comfortable with the most appropriate expenditures. You will also need to check with your supervisor to determine the average amount of funds available for each family to guide your use of the total fund. Below is a list of some of the things for which you may consider utilizing the fund.

1. Paying for the cost of childcare for the family's other children who are not attending treatment.
2. Costs of transportation, including gas money, bus tokens, car repairs, insurance coverage, or even contributing to the purchase of a used car.
3. Clothing for a child who is unwilling to attend treatment in the same hand-me-downs s/he always wears.
4. Recreational activities that provide the child, parent or family with the opportunity to increase their energy level.
5. Give the caregiver relief from the ongoing responsibility for taking care of child(ren) who have emotional and/or behavioral disorders (i.e., respite care).
6.
7.
8.
9.
10.

ADVOCACY IS ... ADVOCACY IS NOT ...

[An excerpt from: Des Jardins, C. (1980). How to organize an effective parent/advocacy group and move bureaucracies. Chicago, IL: Coordinating Council for Handicapped Children.]

Advocacy Is:

1. Helping parents help themselves.
2. Building confidence so parents are able to help themselves.
3. Supporting efforts toward independence.
4. Providing necessary tools for appropriate decisions and appropriate action.
5. Informing parents of their rights.
6. Helping parents get their rights.
7. Analyzing a problem and pinpointing areas of responsibility.
8. Stating options available to resolve a problem.
9. Providing technical assistance and training.
10. Providing assistance in locating appropriate services.
11. Referring to appropriate agencies.
12. Lobbying for necessary legislation.
13. Agitating to get legislation implemented.
14. Organizing for change.
15. Initiating new services.
16. Investigating grievances.
17. Following up on complaints.
18. Going to court when other avenues have failed to get results.
19. Bringing parents and groups together for mutual support and action.
20. Advocating and/or interceding on behalf of parents only when they are unable to help themselves.
21. Advocacy is a partnership with parents, with mutual sharing of information, tasks, and action.

Advocacy Is Not:

1. Taking over a parent's life (or problem) and making all decisions for her/him.
2. Squelching efforts of self-help.
3. Reinforcing feelings of helplessness and dependence.
4. Keeping parents in the dark while doing everything for them.
5. Keeping parents uninformed about their rights, so they will have to rely on the advocate for everything.
6. Discouraging parents from becoming activists.
7. Making excuses for unavailability or inadequacy of services.
8. Making decisions for parents.

Advocacy Is Not (cont.):

9. Controlling parents.
10. Persuading parents to accept "make do" services.
11. Closing the door to parents because "there's nothing I can do to help."
12. Keeping "hands off" of politics.
13. Accepting the status quo when legislation is not implemented.
14. Seeking individual solutions to group problems.
15. Accepting unavailability and inadequacy of services.
16. Denying existence of problems reported.
17. Dropping a complaint after initial contact.
18. filing a lawsuit as the first approach to a problem.
19. Working only with individuals when others share a mutual problem.
20. Interceding on behalf of parents who can help themselves.
21. A parent/child relationship.

SECTION III: DATA COLLECTION PROCEDURES AND OTHER DOCUMENTATION

COLLECTING REFERRALS FOR THE INITIAL INTERVIEW

Before beginning any interviews, Oregon Medicheck (EPSDT) Referral forms (see *Appendix A* for an example), or other acceptable referrals, must be collected. The procedures for collecting these forms is different for each county and outlined below. The Medicheck Referral forms give you the name of the child who has been referred, the child's address and phone number, and the provider to whom the child has been referred. Unfortunately, this form was originally intended to be used with adults, therefore there is no place for the parent's/guardian's name.

(NOTE: Throughout the rest of this manual, the word "parent" will be used to mean the person who is the parent, guardian, or caregiver of the child being referred.)

Lane County:

1. Eugene Hospital Clinic. Arrangements have been made for a copy of each EPSDT Referral form to be accumulated at the Clinic for the Family Associate to pick-up weekly or biweekly.

2. Springfield School District. Arrangements have been made for the Family Associate to review a log notebook of all the children referred for mental health services through EPSDT on a weekly or biweekly basis.

3. Bethel School District. Arrangements have been made for the Family Associate to review a log notebook of all the children referred for mental health services through EPSDT on a weekly or biweekly basis.

4. Cottage Grove Hospital. Arrangements have been made for copies of the EPSDT Referral forms to be mailed to the Family Associate at they are prepared.

Lincoln County:

The Treatment Planning Coordinator (TPC) will give copies of all of the EPSDT Referral forms to the Family Associate as they are received by Lincoln County Mental Health.

Union County:

The details of the referral process have not been delineated completely. It is, however, known that children are primarily referred for mental health services by a parent or CSD caseworker directly to the Union County Center for

Parenting Excellence (CPE), or by a school representative directly to the CPE therapist affiliated with the respective school. The Family Associate will receive referrals in some manner either solely from the pool received by CPE or those and the referrals received by some or all of the school therapists.

CONTACTING FAMILIES FOR THE INITIAL INTERVIEW

In Lane and Lincoln Counties, each Family Associate will mail the parent letter and the project flyer (see *Appendix B* for examples) as soon as the referral is received. As stated in the letters, the Family Associate will call the parent in a couple days. Due to the potentially brief time period between referral and the opportunity to initiate mental health services in Union County, mailing information is not efficient and will not occur. Therefore, the first contact by the Union County Family Associate with the families will be by telephone. The goals of this initial telephone contact (see *Appendix B* for the script) are to:

1. Describe the research project and what their participation involves.

2. Review the eligibility criteria and determine if they can participate. The criteria which exclude a family from participating in the project are:

   a. the referred child is currently in an institutional placement (e.g., residential treatment, correctional facility, or psychiatric hospital).
   b. the referred child is less than 4-years-old, is 18-years-old or older, or is 14- to 17-years-old without parental awareness of their involvement in mental health services.
   c. no parent/caregiver is available for interviews (e.g., emancipated teenager, teenage mother without parental involvement in services).
   d. the referred child is currently participating in mental health services with a duration of three or more sessions.

3. Determine the parent's interest in participating in the research project.

4. Schedule an appointment, giving the parent the option of having you come to their home or finding an alternative location for the interview.

5. Verify the family's address, the child's name, and the spelling of their name. If their name was not on the Referral form, you will need to make sure you get it before you end the conversation.

In order to get a sense for why families choose to not participate in his project, please keep a record of these on the Nonparticipant Log (see *Appendix B*).

BUILDING AND MAINTAINING THE FAMILY ASSOCIATE CASELOAD

To build your caseload, contact new referrals each day until you accumulate a manageable number of families with which to work (e.g., 10 in Lincoln & Union, 20 in Lane). Make sure you only contact as many new referrals each day as you can interview in a short period of time. This is especially important if you are mailing the parent letters before making phone calls. The goal is to interview them before they initiate mental health services (or shortly thereafter).

When you have a opening available for another family, contact any new referrals received that day or later until a parent agrees to participate in the project.

WHEN FAMILY ASSOCIATE SERVICES END

The goal of the Family Associate services is to work with a family to break down barriers which interfere with a family initiating mental health services for their child. For this reason, we would like you to end with a family:

1. When the family/child has participated in three treatment sessions.
   - OR -
2. When the family/child has missed three scheduled appointments.

If a family/child does not neatly fit into either of these two categories, discuss it with your supervisor and Debi to decide when ending is appropriate. Be careful to not hang onto families because you need time to reach the goal of working with 50 (Lincoln & Union) or 100 (Lane) families in one year.

PREPARING FOR THE INITIAL INTERVIEW

Immediately following the initial telephone contact is the best time to prepare for the interview. This includes assigning the family an ID# by selecting the next available research packet, entering the family information on the Research File Checklist (see *Appendix C*), and preparing the documents in the packet. The following things should be done to prepare the research documents before the interview:

1. check that all the Family ID#'s on the documents are the same,

2. record the "Date of the Initial Telephone Contact" and the "Date of Initial Interview" on the Research File Checklist,

3. print the parent's name (correct spelling) on the first line and your name on the second line of the Informed Consent (see *Appendix C*), and

4. print the parent's name (correct spelling) on the Payment Receipt Form (see *Appendix C*) and circle "initial" to identify the interview you will be doing.

COLLECTING THE DATA

Before Leaving To Do The Interview:

Make sure you have all the supplies you need, including the assessment packet, clipboard (or something to write on), some form of identification, the parent's address and telephone number, a copy of the project flyer, and a packet of Spanish assessment materials. You should be dressed neatly and comfortably, looking professional yet not intimidating.

When You Arrive:

You should be on time. Show the parent your business card (or other form of identification) so there is no question about your identity. Assuming they let you in, tell them you will be doing a lot of writing and that it would be helpful to sit at a table with good lighting. (They will also be doing some writing). Use your judgment about what will be most comfortable for everyone. T.V.'s and radios should be turned off if they are distracting. If there are two parents who wish to participate, tell them this is alright as long as one is designated as "primary respondent" and only that person will be completing the questionnaires. This is necessary for consistency across the initial and follow-up interviews.

Informed Consent:

Using the script provided at the beginning of each initial interview, introduce the informed consent portion of the assessment. During this introduction you will be describing the project and the parent's part in it. The goal is to make sure the parent is adequately *informed* about what to expect so they understand what it means to *consent* to participate in the research project. The confidential nature of the information they give us and the limitations of that confidentiality ***must be fully explained*** to the parent so that they are as clear as possible about what will be done with the data and what you would be bound by law to report. This whole process is important because until they sign the Informed Consent form, they have not officially consented to participate in the research project. When the process is completed and the parent has signed the form, give the last copy (pink) to the parent for their records and keep the first two copies to be returned with the rest of the data. (See *Appendix C* for a copy of the Informed Consent form.)

Confidentiality:

You already know a great deal about confidentiality. Nothing about any specific family is to be discussed with anyone other than County Mental Health Program personnel and RRI staff. Documents that have child or family names on them (e.g., Research File Checklist, Informed Consent) should be carefully guarded and secured at all times. Any mailing of materials with names on them should be clearly labelled "CONFIDENTIAL". If information from this research project is to be provided to *anyone* other than County Mental Health Program or project staff, a written release of information must be signed by the parent. Confidentiality will not be maintained in the event you learn of child abuse, if a family member intends to harm her/himself or others, or if information is subpoenaed by a court of law.

Abuse Reporting Requirements And Protocol:

The need for reporting suspected child abuse or neglect should be minimal. But in the event you suspect or witness the occurrence of child abuse or that child neglect poses an imminent danger to the child's well being, Children's Services Division (CSD) for your county must be contacted. It is important that you review the abuse reporting procedures used in your program with your supervisor before meeting with families so you are clear what to do. Listed below are suggestions of steps that you may want to follow for reporting suspected abuse or neglect.

1. Contact your supervisor immediately after the interview when you suspect a need to report. If your supervisor is not available, contact another representative of the County Mental Health Program. Discuss with your supervisor what you should do in evenings or on weekends.

2. Your concerns should be discussed and whether or not a report needs to be made should be determined.

3. If after discussing your concerns with your supervisor it is determined necessary to make a report, call the screener/intake worker on duty at your county's CSD. The best approach is to describe the situation as a "hypothetical" case, allowing the CSD personnel decide whether or not the situation is reportable. If it is reportable, provide the information requested by CSD.

4. Please contact the Project Manager about any abuse concerns or reports made to CSD.

The Oregon Child Abuse Reporting Law is provided for you in *Appendix D.*

Research Interview and Questionnaires:

1. Standardization: This study uses a standardized, structured interview format. Some of the instruments are standardized, meaning they have been utilized in previous studies and have established acceptable reliability and validity. Some of the instruments were developed at RRI and data collected from the Family Connections Project will be used to assist in establishing their reliability and validity. Because we want to quantify the statements people make, you need to ask each respondent the same questions, in the same order, and in as much the same manner (tone of voice, emphasis on certain words, etc.) as possible.

   A structured interview is used in a situation where a representative sample (e.g. families of children with emotional disorders) are asked identical questions about something of interest to researchers (e.g. barriers to mental health services). The need for evaluating and comparing the current service system process to that process enhanced by an intervention necessitates the structure of the interview and questions. Otherwise, there would be no way to state what the *Family Associate* intervention really accomplishes -- if you were to conduct an unstructured or "free flowing" interview, there would be too many variables to sort through. This is why it is so important to read the questions word for word and record responses word for word. (See *Appendix C* for a copy of the Initial Interview.)

   If items need to be reworded to help a parent understand the item, that is allowable. However, the meaning of the item ***CANNOT BE CHANGED.*** Defining words, reducing the complexity of sentence structure, or clarifying the meaning of a phrase is acceptable. Giving a respondent your opinion about how to answer an item, elaborating beyond the content of an item, or giving helpful hints about what the study would like to support with its findings is not acceptable.

   We realize that this is not an easy task to accomplish. While we have instruments with carefully and specifically worded questions, you will be the one in the field who is talking with the respondent. You have a structured/standardized interview package in front of you, but the respondent is on their own and may or may not understand a question or react in the ways we hope s/he will. You will need to pay attention to their responses and reactions to make sure they understand the questions. In addition to the research interview, the two of you are having a conversation and the balance between these types of communication can be somewhat difficult. While you need to read questions word for word, you want to appear to be conversational. This will become easier as you do more interviews and start

to memorize the questions and the format.

2. Interrater Reliability: Interrater (i.e., across interviewers) reliability is essentially the extent to which a group of interviewers have the same understanding of the questions to be asked and the *intent* of those questions, the response coding and recording procedures, what probes to use when respondents do not understand a question, and the sequence of steps to follow from first to last contact with the respondent. Ideally, the way in which you introduce and conduct the interview should be identical to your Family Associate colleagues. In reality, this is not possible given variables such as personalities and communication styles. This is why training, role plays, conference calls, and frequent communication of difficulties are critical. When problems and issues arise during interviews, solutions are determined as a group in order to increase reliability.

   Here are some ways to increase interrater reliability:
   a. Make sure you understand the purpose of the study, the instruments, and the questions.
   b. Don't make assumptions about the instruments. If you are unsure about any instructions or skip patterns during an interview, ask to use the respondent's phone and call the Project Manager. If this is not possible, it is always best to ask all questions. Any questions that were unnecessarily asked can be deleted later.
   c. Listen to the respondent's answers. If it appears that they did not understand a question, say you weren't sure whether you heard their answer correctly and that you are going to repeat the question.
   d. Get a complete answer to each question, especially open ended questions and questions with probes.
   e. Write legibly and edit to make sure there are no missed questions. If a respondent refuses to answer a question, try to determine their reason and write a comment next to that question. It is best to look through each instrument after you finish it since it will still be fresh in your mind.
   f. **Follow the instruments and instructions word for word.** Try not to interpret a question in your own words since this could influence the response you are given. If the respondent is unable to understand a question, record this in the margin and attach a note to the packet to call attention to the problem.

3. Interview Question Directions: Throughout the interview you will find directions (designated by shaded and bolded letters like **this**). These directions are important, giving you information about which items to ask and which items to skip. If you ask items that should have been skipped, it is likely to confuse the parent. The directions also indicate when multiple

responses are accepted and when additional information is needed. You should familiarize yourself with these directions and follow them carefully.

4. Interview Question Probes: Probes are essentially methods for getting additional information from a respondent on an open ended question and for directing or focusing the person's answer. The idea is to get the respondent to give as much information as possible about the topic without directing them with your response to their answer. Examples of probes include pausing, a brief assertion of understanding or interest, and neutral phrases. What probe you use will depend upon what the person has just told you and on your observations and sensitivity to the respondent.

   Pausing after a person has given a one-sentence response to an open ended question has been found to be an effective tool for getting more information. If you don't respond and rather, wait with your pencil poised, you send the message that you are expecting them to tell you more.

   Brief assertions of understanding/interest such as "I see" or "Uh-hm" are often enough to generate more information.

   If the respondent is waiting for you and feels that they have sufficiently answered the question (and you need more information), try a *neutral phrase/question* such as:

   "How do you mean?"
   "I'd like to know more about your thinking on that."
   "Do you have any other reasons for feeling as you do?"
   "Could you tell me more about that?"
   "Anything else?"

   Occasionally, the people become concerned about their performance or unclear about their role in the interview. Examples of helping the respondent feel more comfortable or better understand their role include:

   "We are interested in your opinions."
   "There are no right or wrong answers; we want to know how you feel."
   "Please use the card in choosing your answer."
   "We've already touched on this subject, but let me ask about this."
   "Just let me know if you'd like to stop for a break."
   "Please let me know if a question does not make sense or if you want me to repeat any questions."

Sometimes a person will begin their response with "I don't know." This might be their way of taking more time to think about a question. Give them a minute to think. It could also be that they don't know because they did not understand the question. You should be able to determine the difference by the person's tone of voice. If the person did not understand, reread the question word for word. If they still do not understand, ask them what about the question they do not understand and try to rephrase it carefully.

5. Taking Notes And Recording Respondents' Answers: This is one of the most important aspects of your role. What you record is what gets analyzed later on. Accuracy is crucial. Take plenty of time to ask questions and record answers--there is no need to rush. You may need to ask the respondent to wait briefly while you write down what they say. It is a good idea to keep a log of any problems that arise during the interviews so you can inform project staff about anything that has affected the data. You can write notes in the margins of the instruments to indicate when something unusual has occurred (please notify us if you do this). Be sure to schedule enough time for the interview so you're not pressured to hurry.

6. Nonverbal Cues and Behavior: Since we want to avoid influencing respondents as much as possible, try to pay attention to any nonverbal messages you may be sending. These nonverbal messages include:
   a. communicating through body motion (e.g. leaning forward, eye contact, wringing hands, tapping feet, facial expressions).
   b. the use of space in relation to other people.
   c. the use of time through the pacing of conversation, probing, and pausing.
   d. including the volume of your voice, tone and inflection, the quality of voice (tense, gravelly), and accents, and
   e. the use of touch.

   While we want to convey interest and encourage well rounded answers, we want to minimize messages that could be interpreted negatively (e.g., boredom, irritation, disapproval) or messages that could reinforce certain types of answers (e.g., enthusiasm, agreement). At the same time, you will want to pay attention to nonverbal messages being sent to you from the respondent. Such messages may indicate boredom, a need to take a break, or not understanding a question. You will want to assess whether to respond directly to these types of messages or whether it is better to write a comment in your notes.

7. Keeping Participants on Track and Dealing with Emotional Issues: When you are interviewing the parents, remember to keep their perspective in mind. Some people will be nervous, might feel they need to lead the conversation

(you are, after all, in their home), or may need someone to talk to and will want to tell you all about their situation. You want to let each participant tell some of their story (and many of the open ended questions will allow for this), but you will need to prevent the respondent from going on a tangent after each question. You can say you have some questions that have choices for answers and that you will have time for them to talk about their specific situation as well. Additionally, you can explain that you will have time after the interview is completed to begin discussing how you, as their Family Associate, can learn about them and work on their barriers to the mental health system.

A common problem of the interview process occurs when there is conflict between social/emotional issues which arise during the interview and the demands of the interview. While you want to develop a relationship with the respondent, you initial role is to collect data. Because of the data collection role, the nature of the interviewer-respondent relationship is somewhat professionally distant. You should try to approach the relationship building process in the same way with each respondent while, of course, taking into account their individual differences. Once the data collection is completed, you can shift to your Family Associate role in which a closer, more collaborative relationship is appropriate.

You will need to utilize skills of cultural competence at all times. Depending on factors such as their cultural identity, education and income, history with the children's service delivery system, etc. respondents will have varying responses to certain questions, instruments, traits and behavior of the Family Associate, the structured interview process, as well as the research itself. You will need to be sensitive to the reactions of the respondents in order to appreciate those reactions within the context of their culture.

A SPECIAL NOTE OF CAUTION: If, at any time, you encounter a situation in which you do not feel safe being in a family's home, do not hesitate to end your conversation with them and leave immediately. Tell the parent that you would like to reschedule the interview for another day or that you will be contacting them at a later time. This may become necessary if someone in the home becomes hostile toward you or who appears to be under the influence of alcohol or drugs. We do not want anyone feeling compelled to remain in a dangerous situation in order to collect data or continue to meet the needs of the research project. Your safety comes first! If this does happen, you should review the situation with your supervisor and the Project Manager so the next step can decided.

8. Introducing The Questionnaires: It is important that the respondent is clear about what information each questionnaire is gathering and how they need to be completed. Introduce each questionnaire, pointing out any idiosyncratic qualities each questionnaire has (e.g., skipping the first two pages of the Child Behavior Checklist, completing both the front and the back of the Family Empowerment Scale). Since the instruments are designed for the respondents to complete themselves, you will need to assess whether they can read these instruments. If not, you should read the questions to the these respondents.

9. Reviewing The Data Before Ending The Assessment Process: While the parent is completing the questionnaires you should review the interview, and after the respondent completes the questionnaires you should review them before you move on to you Family Associate role. If more information is needed you can gather it before you leave. Once the Project Manager has the data, if omissions are found or if information is unclear, you will receive a Family Data Completion Form (see *Appendix C*) and will be expected to contact the respondent to rectify the problem. Therefore, making sure that the data is complete and clear before you leave is beneficial for you as well as the project. Here are a few things to review:
   a. Make sure all the necessary items are completed.
   b. Make sure all the written answers are clear and legible.
   c. When a response doesn't appear to fit the question, make sure you get additional information/details/explanation so that the data can be interpreted appropriately.
   d. Make sure an item that the respondent chose to not answer is identified as such, rather than looking like you skipped it accidentally.
   e. Make sure that information is written in the Child Behavior Checklist items that include "Describe:_____".
   f. Encourage a respondent to choose one answer it multiple choices have been circled.

   If the parent cannot take the time to complete the questionnaires during this visit, leave them to be completed. Make a specific appointment to return to collect the completed questionnaires. Inform the parent that you will pay them at that time.

PAYING THE FAMILIES FOR DOING THE INTERVIEW

When all of the materials have been checked and found to be complete, follow the script at the end of the interview to thank them for their time and provide them with the $25 in appreciation for their time. You have been given enough checks to pay all of your families for doing the initial interview. The beginning balance in

each county account is $500 and money will be periodically deposited into the Portland-based checking accounts. When paying a parent, follow these steps:

1. write a $25 check to the respondent,
2. record it in the check register (listing the Family ID# ONLY),
3. write the check number on the Payment Receipt Form,
4. have the respondent sign and date the Payment Receipt Form, and
5. you sign the Payment Receipt Form.

If the parent requires cash, you can give it to her/him after you go to the US Bank branch designated inside the front cover of your check register and withdraw $25 by writing a check for CASH. Make sure that the Family ID# is written on the check and recorded in the check register as "CASH -- *[Family ID#]*". We do not recommend that you carry cash on you.

Send the Project Manager a copy of your check register and any voided checks every two weeks in the data return envelope.

RETURNING THE DATA TO THE PROJECT MANAGER

By this time, you will have already reviewed all the materials for completeness and clarity. Make sure that any problems have been noted on the instruments or on the Research File Checklist. Double-check that all the materials are in the packet by checking off each item on the Research File Checklist. You have been supplied with large manilla envelopes and self-adhesive, postage-paid address labels for mailing the research materials to RRI. Completed data packets need to be mailed to RRI each week you collect data so that it can be reviewed and entered on a timely basis. Additionally, please mail copies of your check register on a biweekly basis and Nonparticipant Logs as they are filled-up.

ONGOING AND FINAL FAMILY ASSOCIATE DOCUMENTATION

Family Associate Activity Log:

As you work with your families, you need to provide us with data regarding the activities you engage in with, or on behalf of those families, as well as the expenditures made from the Family Cash Support Fund. This is done by maintaining a Family Associate Activity Log for each family (see *Appendix C*).

The goal of this documentation is not to record every minute of your time but to provide us with data about the services you provide each family. The first entry for each family agreeing to participate in the project should be the initial telephone contact. Six general categories of activities should be recorded:

1. Scheduling
2. Data Collection
3. Family Cash Support Fund Expenditure
4. Providing Information
5. Finding Resources
6. Providing Support

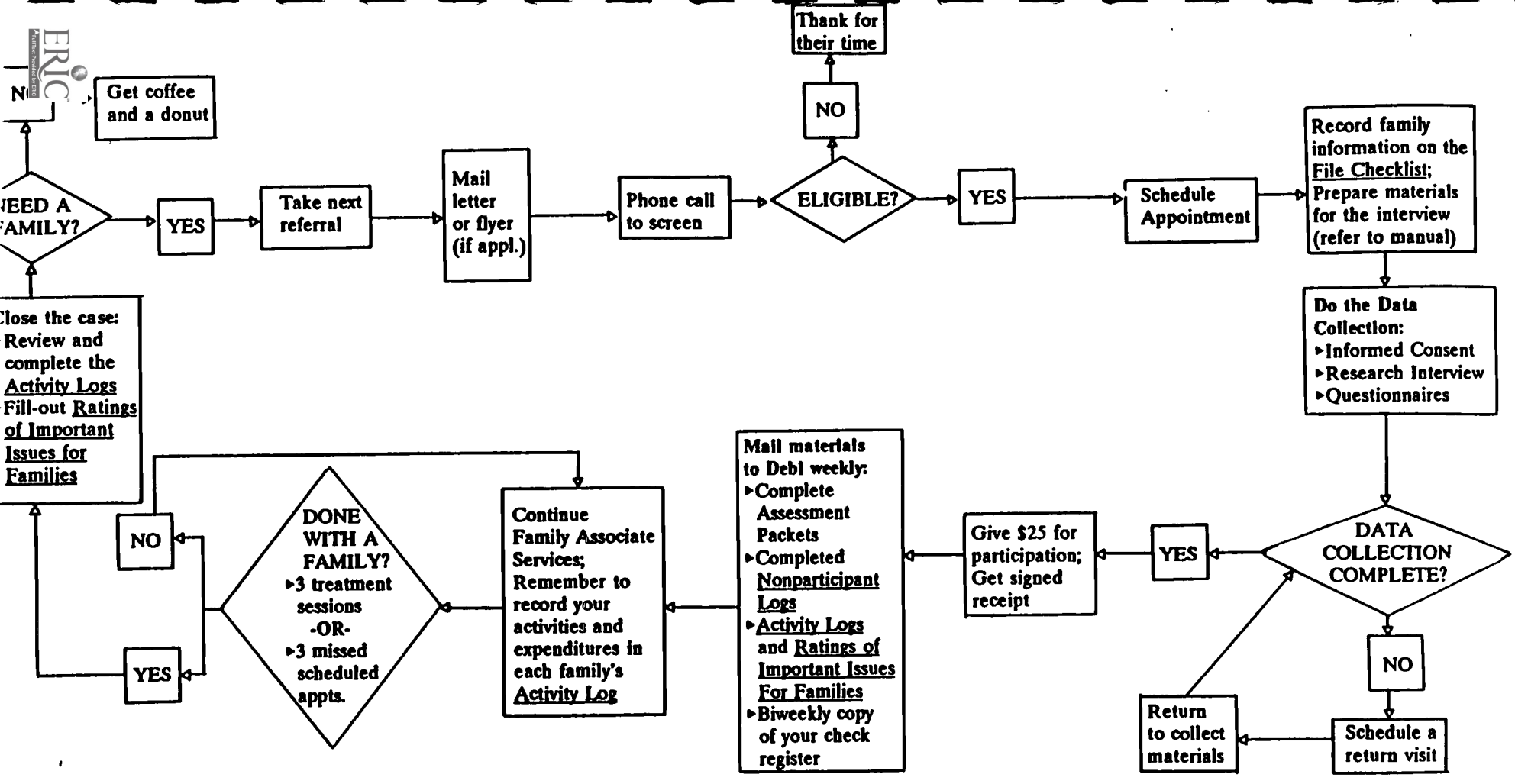
Make sure you complete every section of the Activity Log for each entry. Use the "Comments/Notes" section to elaborate on the entry and to identify the item for which the fund was used. This information will help you recall what you did for the family, help you track things that you need to follow-up on, and provide us with greater detail about the Family Associate role in your county.

Send completed Family Associate Activity Logs to the Project Manager as you complete your work with each family.

Ratings of Important Issues For Families:

The Ratings of Important Issues For Families is a questionnaire that you complete as you close out each case. This gives you the opportunity to identify the barriers that were most prominent for each family, as well as the barriers which you worked on with each family. Since barriers families experience when initiating children's mental health services is the primary focus of this research project, this questionnaire is very important. Please take your time completing this so you can review your records and thoroughly describe each family's experiences and your work with them. This is not an evaluation of your work, but rather your opportunity to provide us with your impressions of each family's barriers to services and the extent to which the Family Associate services impacted those barriers.

Send completed Ratings of Important Issues For Families to the Project Manager as you complete your work with each family.



THINGS TO REMEMBER

Interviewing Burnout:

Interviewing can be stressful and intense. Sometimes parents may be very angry about what is or isn't happening with their child's services. Others may make you feel uncomfortable. To guard against burnout try limiting the number of interviews you do in one day or weekend. If you feel yourself becoming emotionally drained, perhaps it is time to take a break. Talking with your fellow Family Associates, your supervisor, or with project staff to get some coping ideas is always a good option. We will also have opportunities as a group to discuss burnout issues.

Discussion of Questions or Problems:

If any questions or problems arise regarding the interview or specific questionnaires, please contact the Project Manager as soon as possible. If there are any issues which you think should be discussed as a group, let the Project Manager know and we can incorporate them into our training or conference call agendas.

APPENDIX A (from Family Associate Training Manual)

EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT (EPSDT) SERVICES FOR CHILDREN WITH MENTAL HEALTH PROBLEMS

A Summary of the Issue, Background, Estimate of Need and Cost, Current and Future Plans and Activities

Office of Mental Health Services
Office of Child and Adolescent Mental Health Services
Oregon Mental Health and Developmental Disability Services Division

August 15, 1990

THE ISSUE: **Implementation of the 1989 Omnibus Budget Reconciliation Act (OBRA) relating to Early and Periodic Screening, Diagnosis and Treatment (EPSDT) amendments to the Social Security Act.**

BACKGROUND:

The OBRA 89 legislation codifies and expands the requirements of EPSDT that previously were contained in federal regulations (42 C.F.R. 441.56). In regard to mental health services for children, Oregon and other states are now required:

- to require states to allow interperiodic screenings when a medical condition is suspected

  AND

- when a condition is disclosed by an EPSDT screen, to pay for all services allowed under federal Medicaid law, *whether or not* these services are offered to other Medicaid beneficiaries under the state Medicaid plan

OBRA 89 also makes other requirements of the state in regard to EPSDT as a whole. States are required to provide four distinct elements within EPSDT: screening, vision, dental, and hearing services. The states must also set periodicity requirements for each of the four elements which meet "reasonable standards of medical and dental practice, as determined by the state after consultation with recognized medical and dental organizations involved in child health care."

In addition, the states are required to include the following specific elements in the screening service:

By virtue of the child's eligibility for Medicaid-reimbursed services, there are significant environmental and child related factors that influence planning for this population and weighting of prevalence to incorporate these factors. A substantial proportion of the 0-21 years old Medicaid eligible population meet the following risk factors:

- Children from families where there is persistent, intergenerational poverty as reflected in a growing, permanent underclass and an expanding homeless population.
- Children whose parents are themselves children with inadequate resources growing up in a society that assumes that parents have economic, political, and social maturity and sufficiency.
- Children from families in which the prevalence of social diseases such as substance abuse, child abuse, social and psychological pathology, is epidemic.

RECOMMENDATION:

While OBRA 89 places significant responsibilities upon the states in regard to the scope of EPSDT, it also provides an opportunity to restructure the delivery of mental health services to Title XIX eligible children. This restructuring has potential for insuring that children get services which are more appropriate to their needs, more community-based, less restrictive, less costly, and tied to specific outcomes based on a uniform definition of medical necessity.

The goal of this restructuring is to provide a distinct pathway to mental health services for children receiving an EPSDT screen. The pathway provides for a uniform assessment of children with suspected mental health problems and the development of a service plan from this assessment. For children with complex, multi-agency needs and problems, the current Community Coordinating Team responsibility will be broadened to include treatment planning for this population. The following chart shows the proposed system and its components.

ACTION REQUIRED:

This restructuring will be complex and will require legislative, administrative, and programmatic changes. To assure that EPSDT-screened children identified as having mental health problems receive some form of service in the short term, a phased implementation strategy is proposed by the Mental Health and Developmental Disability Services Division.

Phase One: Beginning immediately, EPSDT children referred for outpatient services at community mental health programs will be given priority for evaluation and access to appropriate services.

- The MHDDSD will adopt an emergency amendment to OAR 309-16-000 through 309-16-115 to give children referred to a community mental health program as a result of an EPSDT screen the highest priority for evaluation by September 1, 1990.
- The MHDDSD will revise Part III, Community Treatment Services for Children, of the Intergovernmental Agreement for Mental Health Services, to require that children referred as a result of an EPSDT screen receive highest priority. The Division will amend existing agreements with counties beginning October 1, 1990.
- The Office of Medical Assistance Programs will require county health clinics, contract HMOs and PCOs, private practitioners and other screening sites to provide families with a common referral form to use to gain access to an evaluation by the CMHP. OMAP will disseminate forms to providers by November 1, 1990.
- The Department of Human Resources will submit a request to the September, 1990 E-Board for approval for the expenditure of state funds and positions.

Phase Two: Beginning October 1, 1990, ten treatment planning coordinators (TPCs) will be hired by CMHPs. By November 1, 1990, they will begin taking referrals directly from EPSDT screeners for initial evaluations. These initial evaluations will provide the basis for decisions by the treatment planning coordinators about service needs. By December 1, 1990, moderately disturbed children will be receiving services, and by January 1, 1991, the coordinators will be doing treatment planning for seriously emotionally disturbed children.

Services to children who receive initial evaluations will be home and community based and will generally reflect a level of intensity and parent involvement related to the severity of the disturbance. Children with a moderate level of disturbance will benefit from parent participation services. Estimated to last about eight weeks, these services will include family-based treatment and support services as well as consultation.

The cost per child for services required by the treatment plan are estimated to be $822.

- **Comprehensive Evaluations:** Children who are seriously emotionally disturbed will receive more thorough evaluations, which may be psychiatric, psychological, neurological, or developmental. From these evaluations, treatment plans will be developed. They will involve intensive family participation services and can include child and family treatment and support services, medication management and physician consultation.

  The cost per child for the comprehensive evaluation is estimated to be $890. The services required by the treatment plan are estimated to be $3,630 per child.

A small group of the most seriously emotionally disturbed children may need an even more intensive level of service This might include crisis stabilization, hospitalization and/or out -of-home respite care, as well as case management services, physician services, and child and family treatment and support services.

The cost per child for these services is estimated to be $12,470.

- **Necessary Tasks:** The tasks related to screening, evaluation, and treatment are to:

  - Set criteria for referral for diagnostic and treatment services and prepare for their incorporation into administrative rules by October 1, 1990.
  - Develop elements of the assessment and the plan for treatment and services, including uniform criteria for medical necessity; prepare for their incorporation into administrative rules; amend intergovernmental agreements as needed by November 1, 1990.
  - Assess the need for additional TPCs to provide regional coverage and/or re-evaluate the duties of the TPCs and reconfigure the positions to provide broader coverage by June 1, 1991.

- Seek funding and position authority to establish an EPSDT coordinator within the OMHS by September 1, 1990.

- Amend administrative rules to allow TPCs to give prior authorization for service, by November 1, 1990.

- Amend administrative rules to expand the function of the Community Coordinating Team to include treatment planning for seriously emotionally disturbed children by January 1, 1991.

- Develop an appropriate appeals process in accordance with Administrative Procedures Act and Medicaid General Rules by December 1, 1990.

Financing:

Estimating the cost of services for EPSDT children with mental health problems is difficult. However, based on the numbers of Medicaid children in the state (there are 94,195 children on Medicaid in Oregon between the ages of 0 and 17), it is estimated that the average cost per Medicaid eligible child will be about $98.00 per year, or slightly more than $8.00 per month. .

Research and experience at the national level indicates that children with mental health problems need varying degrees of treatment and services. Using a prevalence rate of 17%, the number of Medicaid children who will need some form of mental health service is estimated to be 16,013. Of these, 1,241 are already receiving state funded mental health treatment services. Because of the newness of the program model, it is estimated that in the first year, only about 50% of the children in need of mental health intervention will be identified during the EPSDT screen. This would put the pool of Medicaid children eligible for evaluation and treatment in the first year at 6,766.

Practical experience also indicates that only about 60% of clients who are referred for evaluations and services follow through to the initial evaluation Consequently, the total number of Medicaid children who will receive mental health services through this EPSDT plan for the first year is estimated to be 4,060. The projected cost of serving any one of these children is $189 per month.

- Necessary Tasks: The tasks related to financing are:

  - Set service rates for children based on severity of need and types of services to be provided by September 1, 1990.

EPSDT DECISION GRID
PREVALENCE AND COST ESTIMATES
October 1, 1990 - June 30, 1991

Annual Estimate

94,195	AFS estimated XIX eligible children in Oregon. Age 0-17
16,013	Estimated Medicaid children in need of mental health services (17%)
8,007	Estimated children referred during screening for evaluation (50%) during first year
-1,241	Estimated Medicaid children now receiving state funded mental health treatment services
6,766	Estimated annual EPSDT pool of Medicaid children
4,060	Estimated children evaluated annually by CMHP's (60%)

Children Served in 1990-91	Service	Start	90-91 Cost
2,704	Children - Initial Evaluation to authorize service	11-1-90	$ 438,480
676	Children - No further treatment required (25%)		-0-
1,352	Children - Moderate disorder (50%)	12-1-90	$ 902,967
676	Children - Comprehensive Evaluation (25%)	1-1-91	$ 451,675
540	Serious/severe disorder (80%)	1-1-91	$ 577,530
136	Acute/severe disorder (20%)	1-1-91	$ 370,923
	Total Service Cost:		$2,741,575
	Less Children's Crisis Services General Fund Offset:		$ -27,779
	Subtotal:		$2,713,796
	Total Management Cost:		$ 460,766
	Local Administration:		$ 47,692
	Total Cost		$3,222,254

Federal Funding (XIX)	$1,966,513
State General Fund	$1,255,751
Total	$3,222,254

Notes: *Funding available for crisis services in MHDDSD budget.

State of Oregon
Department of Human Resources
Office of Medical Assistance Programs

Oregon Medicheck (EPSDT) Referral

Patient Name (last	first	MI)	ID Number
Address			Patient Phone Number
Name of Primary Care Provider			Provider Phone Number
Referral Provider	Specialty Service		Referral Date
Referral Provider's Address			

Requested Disposition of Case

Consultation and Report and

- ☐ Return patient as soon as consultation work-up is completed
- ☐ Return patient after conclusion of care for this illness
- ☐ Assume management for this particular illness
- ☐ Assume future management within your field
- ☐ Medicheck (EPSDT):
  - ☐ Medical Referral
  - ☐ Mental Health Referral
  - ☐ Alcohol and Drug Referral

Explain to Patient

- ☐ Diagnosis
- ☐ Outline Treatment
- ☐ Refer back for interpretation and treatment
- ☐ If surgery is indicated, referring physician requests to
  - ☐ Perform Surgery
  - ☐ Assist
- ☐ Consultant proceed without referring physician's participation

Reason for Referral

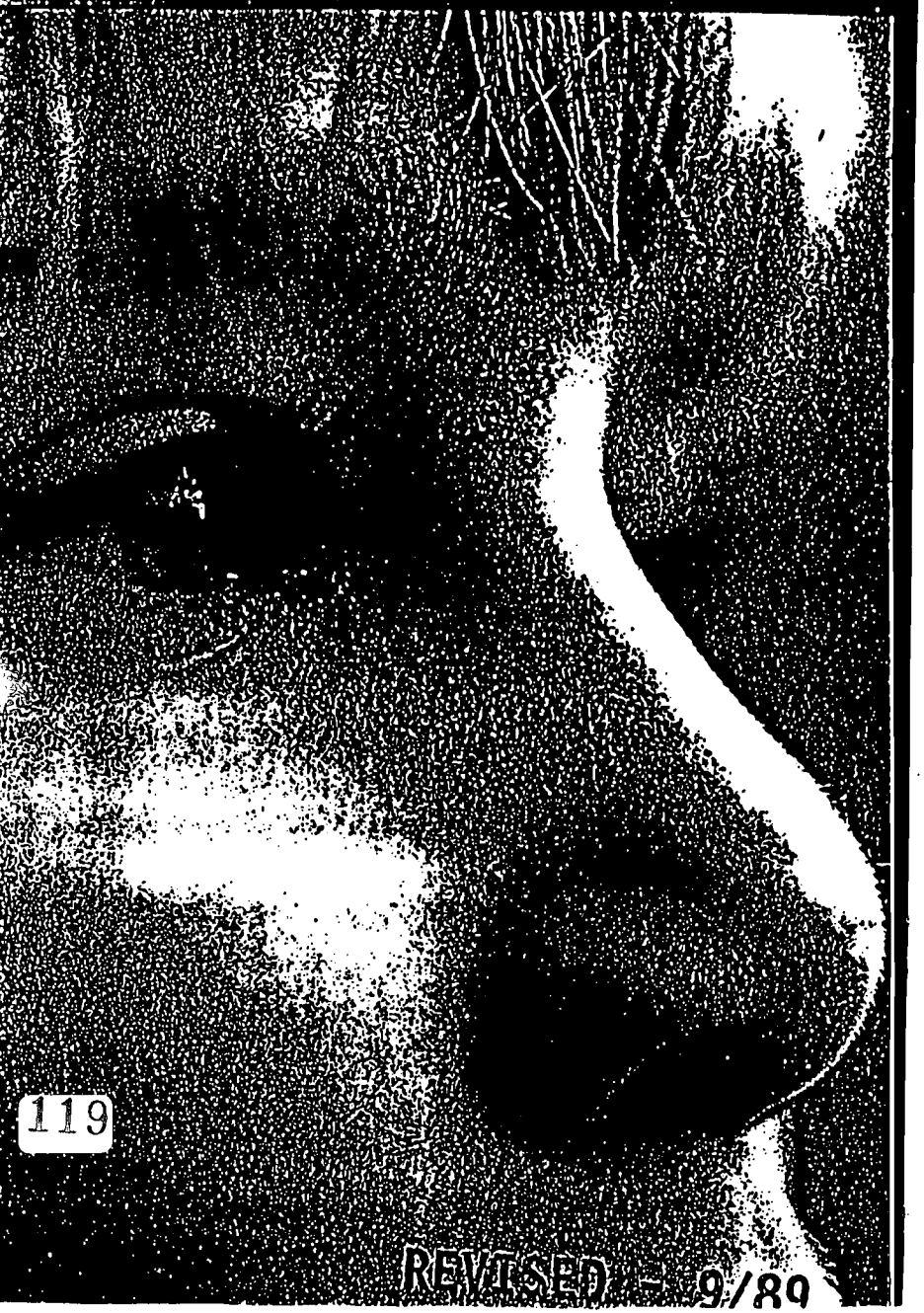
OMAP 3066 (10-90)

PRIMARY CARE PROVIDER

117

118

ILD ABUSE
GLECT



119

REVISED - 9/89

A Social Overview

Child abuse and neglect is recognized as a problem of epidemic proportions. In **1987 and 1988, 17,199** Oregon children were identified as victims of child abuse and neglect. Approximately one fourth of these children were victims of sexual abuse. In **1987 and 1988, thirty-seven** Oregon children died as the result of abuse or neglect. National studies continue to indicate that only a small percent of maltreated children are reported to child protection agencies. Significant numbers of victims remain unidentified, without protection and treatment.

Child abuse has serious consequences which may remain as indelible pain throughout the victim's lifetime. The violence and negligence of parents and caretakers serve as a model for children as they grow up. The child victims of today, without protection and treatment, may become the child abusers of tomorrow.

As with any social issue, child abuse and neglect is a problem for the whole community and achieving the goals of protective services requires the coordination of many resources. Each professional group and agency involved with a family assumes responsibility for specific elements of the Child Protective Services (CPS) process. Children's Services Division works closely with physicians, nurses, education providers, mental health practitioners, law enforcement agencies, and the judiciary. These parties are involved in the identification, reporting, investigation, assessment and treatment of cases of child maltreatment.

OREGON'S CHILD ABUSE REPORTING LAW

APPENDIX D (from Family Associate Training Manual)

120

Who Must Report?

According to Oregon Revised Statute 418.750, "Any public or private official having reasonable cause to believe that any child with whom the official comes in contact in an official capacity has suffered abuse, or that any person with whom the official comes in contact in an official capacity has abused a child shall report or cause a report to be made . . ." Those "public or private officials" include:

- Physician, including any intern or resident
- Dentist
- School employe
- Licensed practical nurse or registered nurse
- Employe of the Department of Human Resources, county health department, community mental health program, a county juvenile department, or a licensed child-caring agency
- Peace officer
- Psychologist
- Clergyman
- Social worker
- Optometrist
- Chiropractor
- Certified provider of day care, foster care, or an employe thereof
- Attorney
- Naturopathic physician
- Firefighters
- Emergency medical technicians

What Information Do I Need To Report?

If known, reports of suspected child abuse shall contain the name, age and address of the child and his/her parents or other persons responsible for the child's care. The nature and extent of abuse, including any evidence of previous abuse and any explanation given by caretakers for injuries should also be reported. Include all information which you believe might be helpful in establishing the cause of the abuse and for identifying the abuser.

Will My Report Be Confidential?

The reporters identity will remain confidential to the full extent allowable by law. If court action is initiated, the reporting person may be called as a witness or the court may order that the reporter's name be disclosed. Only people with firsthand knowledge of the child's situation can provide testimony proving that abuse has occurred.

Can I Be Sued If I Report?

Oregon Law (ORS 418.762) provides that anyone participating in good faith in the making of a report of child abuse and who has reasonable grounds for making the report, shall have immunity from any liability, civil or criminal, that might otherwise be incurred or imposed with respect to such a report. Any such participant shall have the same immunity with respect to participating in any judicial proceeding resulting from such report.

418.750 Duty of officials to report child abuse; exception for privileged communications. Any public or private official having reasonable cause to believe that any child with whom the official comes in contact in an official capacity has suffered abuse, or that any person with whom the official comes in contact in an official capacity has abused a child shall report or cause a report to be made in the manner required in ORS 418.755. Nothing contained in ORS 40.225 to 40.295 shall affect the duty to report imposed by this section, except that a psychiatrist, psychologist, clergyman or attorney shall not be required to report such information communicated by a person if the communication is privileged under ORS 40.225 to 40.295. [1971 c.451 §3; 1973 c.110 §2; 1975 c.644 §4; 1981 c.892 §94]

418.755 Report content; notice of report to law enforcement agencies and local Children's Services Division office. An oral report shall be made immediately by telephone or otherwise to the local office of the Children's Services Division or to a law enforcement agency within the county where the person making the report is at the time of his contact. If known, such reports shall contain the names and addresses of the child and his parents or other persons responsible for his care, the child's age, the nature and extent of the abuse (including any evidence of previous abuse), the explanation given for the abuse and any other information which the person making the report believes might be helpful in establishing the cause of the abuse and the identity of the perpetrator. When a report is received by the Children's Services Division the division shall immediately notify a law enforcement agency within the county where the report was made. When a report is received by a law enforcement agency, the agency shall immediately notify the local Children's Services Division within the county where the report was made. [1971 c.451 §4; 1975 c.644 §7; 1977 c.741 §1]

418.760 Duty of division or law enforcement agency receiving report; investigation; protective services for child. (1) Upon receipt of oral report required under ORS 418.750, the Children's Services Division or the law enforcement agency shall immediately cause an investigation to be made to determine the nature and cause of the abuse of the child. If the investigation is conducted on public school premises, the school administrator shall first be notified that the investigation is to take place unless the school administrator is a subject of the investigation. The school administrator or a school staff member designated by the administrator may, at the investigator's discretion, be present to facilitate the investigation. The Children's Services Division or the law enforcement agency making the investigation shall be advised of the child's handicapping conditions, if any, prior to any interview with the affected child. A school administrator or staff member is not authorized to reveal anything that transpires during an investigation in which the administrator or staff member participates nor shall the information become part of the child's school records, except that the school administrator or staff member may testify at any subsequent trial resulting from the investigation and may be interviewed by the respective litigants prior to any such trial.

(2) If the law enforcement agency conducting the investigation finds reasonable cause to believe that abuse has occurred, the law enforcement agency shall notify by oral report followed by written report the local office of the Children's Services Division. The Children's Services Division shall provide protective social services of its own or of other available social agencies if necessary to prevent further abuses to the child or to safeguard the child's welfare.

(3) If a child is taken into protective custody by the Children's Services Division, the division shall promptly make reasonable efforts to ascertain the name and address of the child's parent or guardian.

418.770 Confidentiality of records; when available to others. (cont.) (4) No officer or employe of the Children's Services Division or any person or entity to whom disclosure is made pursuant to subsections (1) and (2) of this section shall release any information not authorized by subsections (1) and (2) of this section. [1971 c.451 §7; 1973 c.306 §2; 1975 c.644 §10; 1977 c.741 §4; 1983 c.153 §1; 1985 c.601 §1]

418.775 Certain privileges not grounds for excluding evidence in court proceedings on child abuse. (1) In the case of abuse of a child, as defined in ORS 418.740, the psychotherapist-patient privilege, the physician-patient privilege, the privileges extended to nurses, to staff members of schools and to registered clinical social workers and the husband-wife privilege created by ORS 40.230 to 40.255 shall not be a ground for excluding evidence regarding a child's abuse, or the cause thereof, in any judicial proceeding resulting from a report made pursuant to ORS 418.750.

(2) In any judicial proceedings resulting from a report made pursuant to ORS 418.750, either spouse shall be competent and compellable witness against the other. [Formerly 146.770; 1973 c.110 §1; 1975 c.644 §11; 1981 c.892 §95]

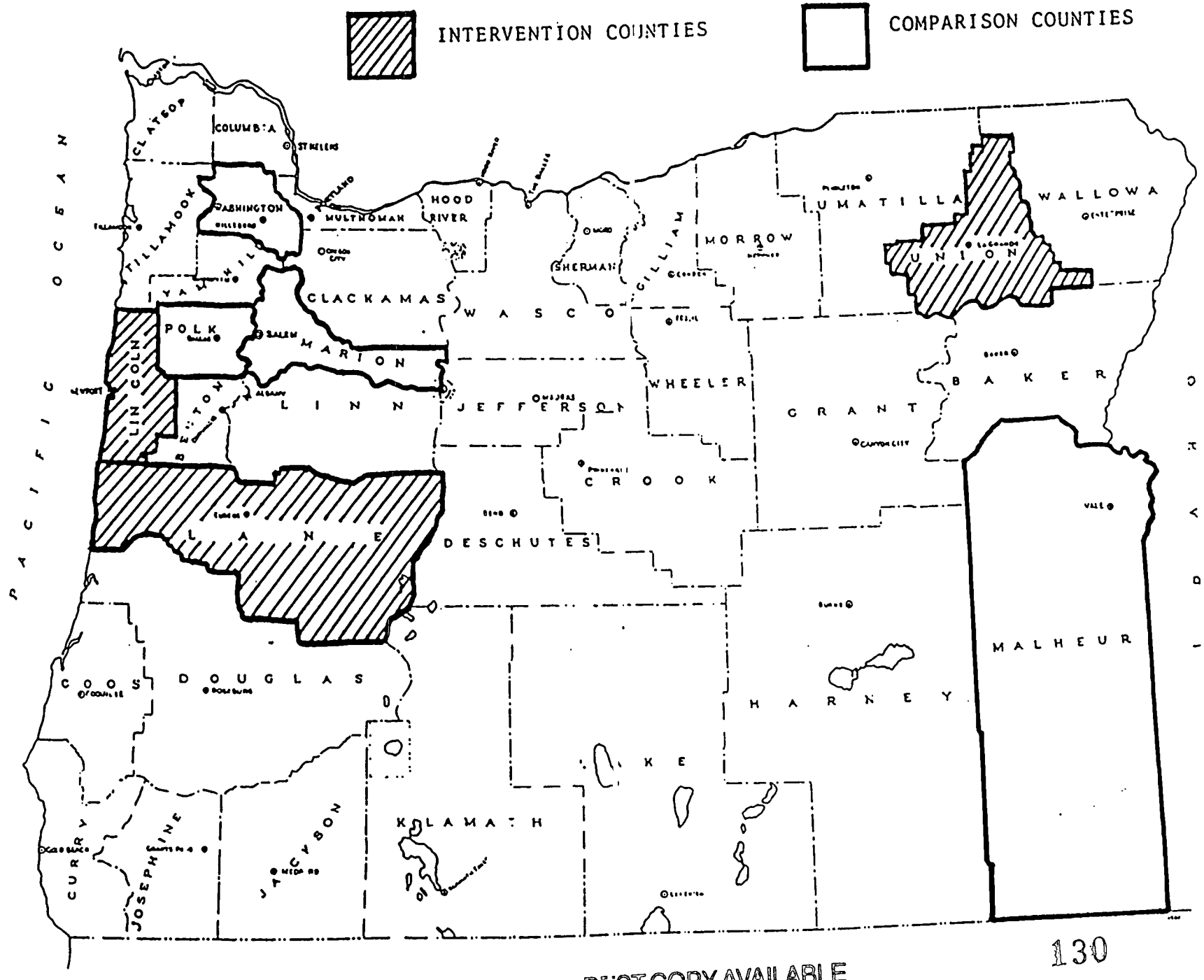
PENALTIES

418.990 Criminal penalties.

(5) A person who violates ORS 418.750 commits a violation punishable by a fine not exceeding $1,000. Prosecution under the subsection may be commenced at any time within 18 months after commission of the offense.

(6) A person who violates ORS 418.770(3) commits a violation punishable by a fine not exceeding $1,000.

(7) Violation of ORS 418.215, 418.250(1) or 418.327(3) is a Class A misdemeanor. Each day of violation is a separate offense.



APPENDIX B

Oregon Map with Family Connections Project Counties Highlighted

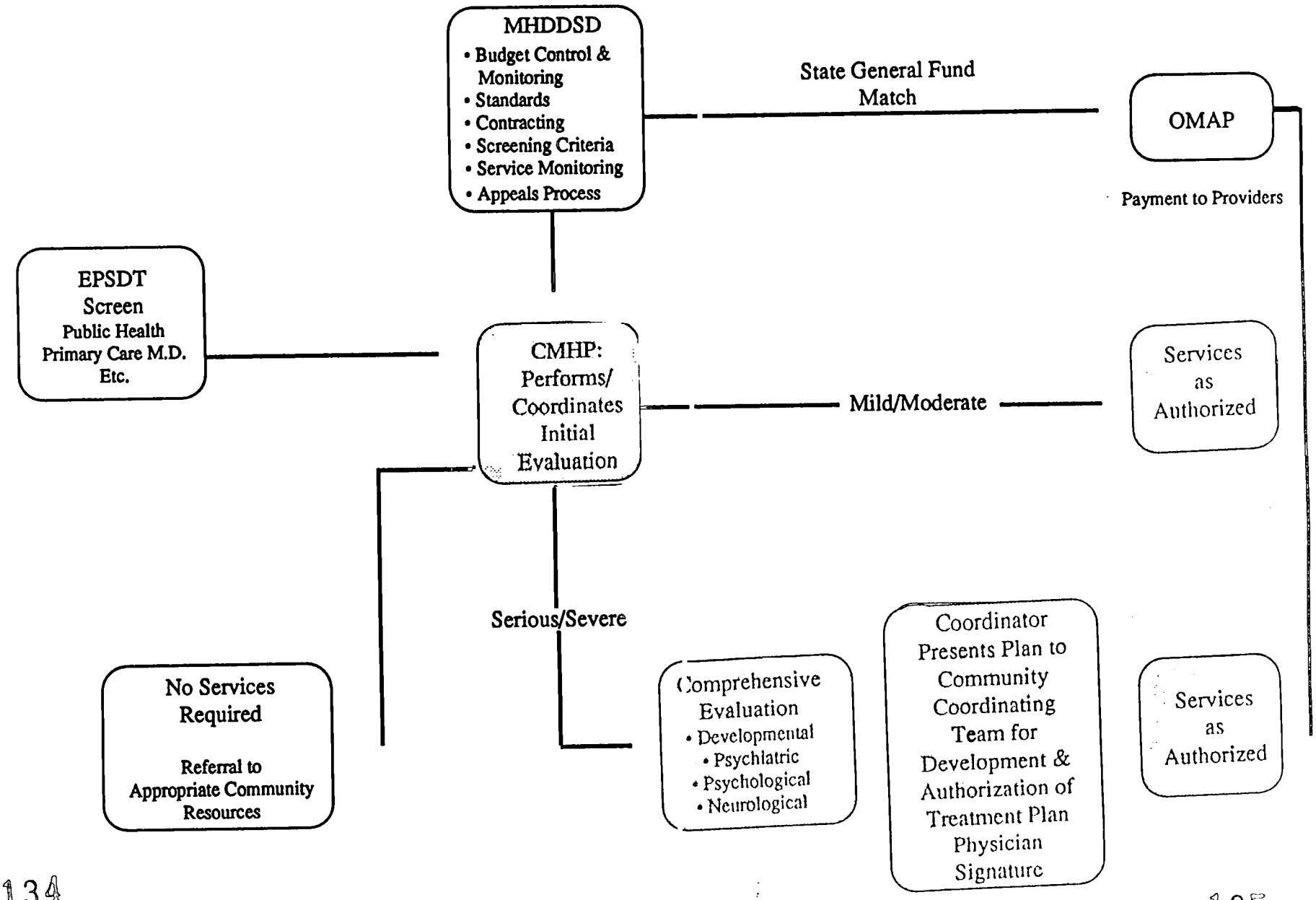
Barriers to *Continuing* Mental Health Services

Group	Barrier (rank ordered by group)	n	%
Intervention (n = 59)	Disliked Therapist/Program	7	35
	Did Not Think MHS Were Helping	7	35
	Disagreed with Diagnosis/Treatment	7	35
	Time Conflict	6	30
	Child Refused Treatment	6	30
	Transportation Problems	6	30
	Family Moved	6	30
	Were Not Meeting Cultural Needs	5	25
	Family Problems	4	20
	Discomfort Being Assoc with MHS	3	15
	Child Care Problems	2	10
	Disrupted Regular Family Routine	2	10
	Too Far To Travel	1	5
	Conflict With Religious Beliefs	1	5
	Problems Connecting with MHS	1	5
Comparison (n = 70)	Time Conflict	6	29
	Did Not Think MHS Were Helping	6	29
	Disliked Therapist/Program	4	19
	Family Problems	3	14
	Problems Connecting with MHS	3	14
	Child Refused Treatment	3	14
	Could Not Afford	3	14
	Disrupted Regular Family Routine	2	10
	Transportation Problems	1	5
	Would Not Meet Cultural Needs	1	5
	Moved	1	5
	Other	2	10

APPENDIX C

EPSDT Referral Process Flow Chart

SCREENING, EVALUATION AND TREATMENT PATHWAY



APPENDIX D

Introductory Letter to Caregivers
and Family Connections Project Flyer
(Intervention and Comparison Group Versions)
(English and Spanish Versions)

INTERVENTION GROUP VERSION
- Printed on Union County letterhead
- Spanish translation printed on back

Dear Parent:

I work with Union County Center for Parenting Excellence. I understand that your child has been referred for mental health services. There is a research project that is designed to provide information and support to families who are just getting started with mental health services in this county. As a *Family Associate*, I work with parents to help them, for example, reduce confusion about the mental health services process, understand what will happen at the different steps of the process, find resources to get to the mental health services, and connect with parent support groups of parents who have been through the mental health process before. I have attached a description of our project (the purple sheet). Please note that we are paying $25 for each interview.

We would like to interview you if your child, who was referred for mental health services, is 4- to 17-years-old.

You may choose whether or not to take part in the project. If you choose not to be in the project, your child's mental health services will not be affected in any way.

You do not have to make a decision right now. All I am asking you to do is to let us call you to give you more information and answer any questions you might have. If you are willing to get a phone call, please fill-out the Reply Form (yellow half-sheet) and send it to me in the attached postage-paid envelope as soon as possible (no later than two weeks from when you get this letter). Once I receive that from you, I will call you.

Thank you for your time and willingness to consider being in the Family Connections Project.

Best wishes,

Pam Hall
Family Associate

Enclosures

Estimada/o Padre de Familia:

Yo trabajo en el Centro Para la Excelencia Paterna del Condado Union (Union County Center for Parenting Excellence). Me han informado que a su niño/a, lo han referido a servicios de salud mental. Hay una investigación cuya meta es dar información y apoyo a las familias que están empezando a recibir servicios de salud mental aquí en el condado. Como una Asociada Familiar, yo trabajo con los padres de familia con fines de, por ejemplo: aclarar confusión sobre el proceso de los servicios de salud mental; enterarlos de los diferentes sucesos en diferentes etapas del proceso; encontrarles recursos para que logren obtener los servicios de salud mental; y ponerles en contacto con grupos de apoyo de padres de familia que han tenido experiencia con el proceso antes. He incluído una descripción de nuestro proyecto (la hoja morada). Fíjese Ud. que pagamos $25 por cada entrevista a las familias.

Quisiéramos entrevistarle a Ud. si su niño que ha sido referido a servicios de salud mental tiene de 4 a 17 años de edad.

Ud. puede escojer participar o no. Si escoje no participar en el proyecto, los servicios de salud mental de su niño no se afectarán de ninguna manera.

Ud. no tiene que hacer una decisión ahora. Unicamente le pido que nos deje que le hablemos para darle más información y contestar cualquier pregunta que pueda tener. Si Ud. está dispuesto a recibir una llamada, favor de llenar la Forma de Respuesta (media hoja amarilla) y mandármela en el sobre con timbre pagado que incluí tan pronto posible (favor de no demorar más de dos semanas después de haber recibido esta carta). Ya que reciba su forma, le pediré a nuestro entrevistador que se comunique con Ud.

Gracias por su tiempo y por considerar participar en el proyecto.

Con mis mejores deseos,

Pam Hall
Asociada Familiar

Anexos

INTERVENTION GROUP VERSION
- Spanish translation printed on back

FAMILY CONNECTIONS PROJECT

WHAT IS THE *FAMILY CONNECTIONS PROJECT*?

The *Family Connections Project* is a research project which is studying the helpfulness of supportive services for families just getting started with mental health services. These supportive services are provided by a *Family Associate*.

WHAT IS A *FAMILY ASSOCIATE*?

The *Family Associate* is a parent, working for the County Mental Health office, who has experience with the mental health service system for children and families. The *Family Associate* works with parents of children referred for mental health services.

WHAT WOULD MY FAMILY GET IF I CHOOSE TO BE IN THE PROJECT?

The *Family Associate* would provide your family with:

1) information about the mental health evaluation and services your child may receive,
2) social and emotional support,
3) connections with other parents of children who have emotional or behavioral difficulties, and
4) ways of getting resources that your family may need to help you get your child to the mental health services.

WHAT WOULD I BE ASKED TO DO IF I CHOOSE TO BE IN THE PROJECT?

We would like to include you in this project if your child, who was referred for mental health services, is 4- to 17-years-old. If you decide that you want to be in the project, the *Family Associate* will briefly interview you about your child and any experiences you have had with the mental health service system. She will also ask you to fill-out some checklists about your child's behavior and your family's coping style. For doing this, you will receive $25. About 2-4 months later, a different person will interview you about the mental health services you have received and what you thought about them. Also, you will be asked to fill-out the same checklists you did the first time. For doing this, you will receive another $25.

WHAT IF I DO NOT WANT TO BE IN THE PROJECT?

You will not receive the *Family Associate* services and you will not do the two interviews nor fill-out any of the checklists. Your family's mental health services will not be changed in any way.

WHO CAN I CALL IF I HAVE QUESTIONS?

If you have any questions or concerns about the research project, contact either Debi Elliott or Nancy Koroloff at the Regional Research Institute for Human Services at Portland State University, 725-4040 or 1-800-547-8887 (extension 4040).

PROYECTO "CONEXIONES FAMILIARES"

¿QUE ES EL PROYECTO "CONEXIONES FAMILIARES"?

El Proyecto "Conexiones Familiares" es un proyecto investigativo que está estudiando la ayuda de servicios de apoyo para familias que están empezando a recibir servicios de salud mental. Una Asociada Familiar proveé estos servicios de apoyo.

¿QUE ES UNA *ASOCIADA FAMILIAR*?

Una *Asociada Familiar* es una madre de familia, empleada por la oficina de salud mental del Condado, quien tiene experiencia con el sistema de salud mental para niños y familias. *La Asociada Familiar* trabaja con los padres de los niños que se refieren a los servicios de salud mental.

¿QUE RECIBIRIA MI FAMILIA SI ESCOJO PARTICIPAR EN EL PROYECTO?

La Asociada Familiar proveerá a su familia:

(1) Información sobre la evaluación de salud mental y servicios que su niño podría recibir.
(2) Apoyo social y emocional.
(3) Conexiones con otros padres de niños que tienen dificultades emocionales o de comportamiento, y
(4) Maneras de procurar recursos que su familia podría necesitar para ayudar a lograr que su niño obtenga los servicios de salud mental.

¿QUE SE PEDIRIA DE MI SI ESCOJO PARTICIPAR EN EL PROYECTO?

Quisiéramos entrevistarle a Ud. si su niño que ha sido referido a servicios de salud mental tiene de 4 a 17 años de edad. Si Ud. escoje participar en el proyecto, *La Asociada Familiar* le hará una breve entrevista sobre su niño y cualquier experiencia que haya tenido con el sistema de servicios de salud mental. También le pedirá que Ud. cheque o llene algunos cuestionarios sobre el comportamiento de su niño y el modo que su familia lo soporta. Ud. recibirá $25 por hacer esto. Despues de 2 a 4 meses, otra persona le entrevistará sobre los servicios de salud que ha recibido, y que opinó Ud. de ellos. Y le pedirá que vuelva a llenar los mismos cuestionarios que hizo la primera vez, y recibirá otros $25.

¿Y SI NO QUIERO PARTICIPAR EN EL PROYECTO?

No recibirá los servicios de la Asociada Familiar ni hará las dos entrevistas ni llenará ningunos de los cuestionarios. Los servicios de salud mental de su familia no cambiarán de ninguna manera.

¿A QUIEN PUEDO LLAMAR SI TENGO PREGUNTAS?

Si tiene algunas preguntas o dudas sobre el proyecto investigativo, comuníquese con Debi Elliott o Nancy Koroloff en la "Regional Research Institute for Human Services" (instituto regional de investigaciones para los servicios humanos) en "Portland State University" (universidad estatal de [illegible]and), 725-4040 o 1-800-547-8887 extensión 4040.

Portland State University

Regional Research Institute for Human Services
Mailing Address: P. O. Box 751 Portland, OR 97207-0751
(503) 725-4040 / Facsimile (503) 725-4180
Street Address: 1912 S.W. Sixth Avenue, Suite 120 Portland, OR 97201

Date: _____

COMPARISON GROUP VERSION
- Spanish translation printed on back

Dear Parent:

I would like to invite you to be in a research project called the Family Connections Project. It is studying the needs of families who are just getting started with mental health services for their child. The Washington County Mental Health Program is working with the Regional Research Institute at Portland State University on the project.

I understand that your child has been referred for mental health services. You can provide us with important information about what a family may need to make this experience easier. I have attached a description of our project (the purple sheet). Please note that we are paying $25 for each interview. I will be calling you in the next couple of days to describe the project in more detail and to see if you want to be in the project.

We would like to interview you if your child, who was referred for mental health services, is 4- to 17-years-old and has not had more than 3 mental health appointments.

You may choose whether or not to take part in the project. If you choose not to be in the project, your child's mental health services will not be affected in any way.

I look forward to talking with you.

Best wishes,

Evie Oxman
Research Interviewer
725-5829 or 1-800-547-8887 Extension 5829

Attachments

FECHA: _____

Estimada/o Padre de Familia:

Le invito a participar en un proyecto investigativo que se llama el Proyecto "Conexiones Familiares" (Family Connections Project) y que está estudiando las necesidades de familias que están empezando a recibir servicios de salud mental para su niño/a. El Programa de Salud Mental del Condado de Washington (Washington County Mental Health Program) está trabajando con la "Regional Research Institute" (instituto regional de investigaciones) de "Portland State University" (universidad estatal de Portland) en el proyecto investigativo.

Me han informado que a su niño/a, lo han referido a servicios de salud mental. Ud. puede proveer nos información importante sobre lo que una familia pueda necesitar para hacer esta experiencia más fácil, y, como fue la experiencia de Ud. He incluído una descripción de nuestro proyecto (la hoja morada). Fíjese Ud. que pagamos $25 por cada entrevista a las familias. En unos días me comunicaré con Ud. para describir el proyecto en más detalle, y para averiguar si Ud. quiere participar.

Quisiéramos entrevistarle a Ud. si su niño que ha sido referido a servicios de salud mental tiene de 4 a 17 años de edad y no ha tenido más que 3 citas de salud mental.

Ud. puede escojer participar o no. Si escoje no participar en el proyecto, los servicios de salud mental de su niño no se afectarán de ninguna manera.

Espero con agrado hablar con Ud.

Con mis mejores deseos,

Evie Oxman
Entrevistador
725-5829 o 1-800-547-8887 extensión 5829

Anexos

FAMILY CONNECTIONS PROJECT

WHAT IS THE *FAMILY CONNECTIONS PROJECT*?

The *Family Connections Project* is a research project which is studying the needs of families just getting started with mental health services.

WHAT WOULD I BE ASKED TO DO IF I CHOOSE TO BE IN THE PROJECT?

We would like to interview you if your child, who was referred for mental health services, is 4- to 17-years-old. If you decide that you want to be in the project, an interviewer will ask you some questions about your child and any experiences you have had with the mental health service system. The interviewer will also ask you to fill-out some checklists about your child's behavior and how your family copes. For doing this, you will receive $25. About 2-4 months later, the same person will interview you about the mental health services you have received and what you thought about them. Also, you will be asked to fill-out some checklists. For doing this, you will receive another $25.

WHAT IF I DO NOT WANT TO BE IN THE PROJECT?

Choosing not to be in the project means you will not do the two interviews nor fill-out any of the checklists. Your family's mental health services will not be changed in any way.

WHO CAN I CALL IF I HAVE QUESTIONS?

If you have any questions or concerns about the research project, contact either Debi Elliott or Nancy Koroloff at the Regional Research Institute for Human Services at Portland State University, 725-4040 or 1-800-547-8887 (extension 4040).

PROYECTO "CONEXIONES FAMILIARES"

¿QUE ES EL PROYECTO "CONEXIONES FAMILIARES"?

El Proyecto "Conexiones Familiares" es un proyecto investigativo que está estudiando las necesidades de las familias que están empezando a recibir servicios de salud mental.

¿QUE SE PEDIRIA DE MI SI ESCOJO PARTICIPAR EN EL PROYECTO?

Quisiéramos entrevistarle a Ud. si su niño que ha sido referido a servicios de salud mental tiene de 4 a 17 años de edad. Si Ud. escoje participar en el proyecto, un entrevistador le hará algunas preguntas sobre su niño y cualquier experiencia que haya tenido con el sistema de servicios de salud mental. También le pedirá que Ud. cheque o llene algunos cuestionarios sobre el comportamiento de su niño y como su familia lo soporta. Ud. recibirá $25 por hacer esto. Después de 2 a 4 meses, otra persona le entrevistará sobre los servicios de salud que ha recibido, y que opinó Ud. de ellos. Y se pedirá que llene unos cuestionarios y recibirá otros $25.

¿Y SI NO QUIERO PARTICIPAR EN EL PROYECTO?

El escoger no participar en el proyecto significa que no hará las dos entrevistas ni llenará ningunos de los cuestionarios. Los servicios de salud mental de su familia no cambiarán de ninguna manera.

¿A QUIEN PUEDO LLAMAR SI TENGO PREGUNTAS?

Si tiene algunas preguntas o dudas sobre el proyecto investigativo, comuníquese con Debi Elliott o Nancy Koroloff en la "Regional Research Institute for Human Services" (instituto regional de investigaciones para los servicios humanos) en "Portland State University" (universidad estatal de Portland), 725-4040 o 1-800-547-8887 extensión 4040.

APPENDIX E

Initial Interview Telephone Scripts
(Family Associate and Research Interview Versions)

Follow-Up Interview Telephone Scripts

FAMILY CONNECTIONS PROJECT

FAMILY ASSOCIATE SCRIPT FOR INITIAL TELEPHONE CONTACT

(INITIAL INTERVIEW -- INTERVENTION)

Hello. My name is _____. I am with _____ County Mental Health. I'm working on a special research project called the Family Connections Project.

(Use whatever is appropriate to your county:)

We sent you a letter introducing this Project a few days ago. Do you remember seeing that?

-OR-

We have receive a referral on ***(child's name)***, and I am following up on that.

I would like to tell you about the project and then, if you are interested, we can see if your family fits the criteria to be in the project.

The Family Connections Project is a project designed to answer questions and provice other support for families who are just getting started with mental health services. We know that sometimes it is hard for families who have just been referred to understand what is going to happen. If you decide to be a part of the Family Connections Project, I would work with you to give you information about what to expect, answer any questions you might have, and help you get to the clinic. Anything that might be helpful whilc **(child's name)** is getting started with mental health services.

The project also involves interviewing families about what it's like to get started in mental health services and how helpful the services are that we provide you. If you decide to be a part of the Family Connections Project, you will be asked to take part in two research interviews. I would do the first one with you in the next few days. The second interview would be done in three to four months by another person. Each interview would take between an hour to an hour and 1/2, and you will be paid $25 for each interview. Your choice about whether or not to be in this project will <u>not</u> affect your child's mental health services in any way.

<u>WOULD YOU LIKE TO BE A PART OF THE FAMILY CONNECTIONS PROJECT?</u>

A. ***(IF NO:) Accept a "no" response, thank them for their time, hang up.)***

(If respondent seems willing to talk, you might ask:) Do you have any concerns that we should know about as we talk with other families?

B. ***(IF PARENT HESITATES OR SEEMS UNSURE:)***

Let me give you some more information about the project or the interviews.

- OR -

Do you have any questions that I could answer?

- OR -

Could I mail some information to you and give you a call when you have had time to go over it?

C. ***(IF YES:)*** Let me check a few things with you to make sure your family is eligible.

I understand that ***(child's name)*** is the child being referred for mental health services. Is that correct?

1. Does ***(child's name)*** have a medical card? ____ Yes ____ No
   (IF NO, probe to see if they are clear about what a medical card is. <u>Description</u>: 1/2 sheet, computer printed, mailed each month, must show at the doctor's office.)

   (IF NO MEDICAL CARD → <u>NOT ELIGIBLE</u>.*)

2. Is ***(child's name)*** 4 to 18 years old? ____ Yes ____ No

   (IF CHILD IS YOUNGER OR OLDER → <u>NOT ELIGIBLE*.</u>)

3. Is ***(child's name)*** currently receiving any mental health services? ____ Yes ____ No
   (Verify that they are clear about what mental health services are.)

   (IF YES, ask how long. IF CHILD HAS BEEN EVALUATED AND IS PAST THE THIRD REGULARLY SCHEDULED TREATMENT SESSION → <u>NOT ELIGIBLE.</u>*)

4. Is ***(child's name)*** currently living with you? ____ Yes ____ No
   (IF NO:) Where is s/he living?

   (IF CHILD IS CURRENTLY LIVING IN A RESIDENTIAL TREATMENT CENTER OR AN INSTITUTION → <u>NOT ELIGIBLE</u>.*)

   (If child is living with another family:) Will you be the person responsible for getting ***(child's name)*** to mental health services? ____ Yes ____ No

   (IF NO → <u>NOT ELIGIBLE</u>.*)

   OK. Your family fits the criteria to be in this project. Let's go ahead and schedule a time I can see you. Would you like me to come to your home to do the interview?

****(WHEN A CHILD IS NOT ELIGIBLE:)***
I am sorry, but we are including only children who _____ ***(<u>criteria not met.</u>)*** _____. Thank you for your time.

(If the person is upset about not being eligible, explain that the research project is limited to children who have certain characteristics. Remind the person that the child's/family's mental health services will be unaffected. If they continue to be upset, let them know you will give their name and phone number to the Project Manager, who will call them to discuss the situation. <u>(Remember</u> to call Debi with this information.)

SCRIPT FOR INITIAL TELEPHONE CONTACT

(INITIAL INTERVIEW – COMPARISON)

Hello. My name is _____. I am with Portland State University. I'm working in a special research project called the Family Connections Project, which the _____ County Mental Health program is helping us with. ***(Use whatever is appropriate to your county:)***

I sent you a letter introducing this Project a few days ago. Do you remember seeing that?

-OR-

You returned our reply form, and I am following up on that.

-OR-

The _____ County Mental Health program received a referral for **(child's name)** and I am following up on that.

I would like to tell you about the project and then, if you are interested, we can see if your family fits the criteria to be in the project. **[NOTE: If person is Spanish-speaking, see last page.]**

The Family Connections Project is a project which is studying the needs of families who are just getting started with mental health services. We know that sometimes it is hard for families who have just been referred to understand what is going to happen. We would like you to tell us what it's like for you and your family to get started in mental health services.

If you decide to be a part of the Family Connections Project, you will be asked to take part in two research interviews. I would do the first one with you in the next few days. I will call you in three to four months to schedule the second interview. Each interview would take between an hour to an hour and 1/2, and you will be paid $25 for each interview. If you choose to withdraw from the project before the second interview, you will be paid for the first interview only. Your choice about whether or not to be in, or continue in, this project will not affect your child's mental health services in any way.

WOULD YOU LIKE TO BE A PART OF THE FAMILY CONNECTIONS PROJECT?

A. ***(IF NO:) Accept a "no" response, thank them for their time, hang up.)***

(If respondent seems willing to talk, you might ask:) Do you have any concerns that we should know about as we talk with other families?

B. ***(IF PARENT HESITATES OR SEEMS UNSURE:)***

Let me give you some more information about the project or the interviews.

- OR -

Do you have any questions that I could answer?

- OR -

Could I mail some information to you and then give you a call when you have had time to go over it?

C. ***(IF YES:)*** Let me check a few things with you to make sure your family is eligible.

I understand that ***(child's name)*** is the child being referred for mental health services. Is that correct?

1. Does ***(child's name)*** have a medical card? ____ Yes ____ No
   (IF NO, probe to see if they are clear about what a medical card is. <u>Description</u>: 1/2 sheet, computer printed, mailed each month, must show at the doctor's office.)
   (IF NO MEDICAL CARD → <u>NOT ELIGIBLE</u>.*)

2. Is ***(child's name)*** 4 to 18 years old? ____ Yes ____ No
   (IF CHILD IS YOUNGER OR OLDER → <u>NOT ELIGIBLE*.)</u>

3. Is ***(child's name)*** currently receiving any mental health services? ____ Yes ____ No
   (Verify that they are clear about what mental health services are.)

   (IF YES, ask how long. IF CHILD HAS BEEN EVALUATED AND IS PAST THE THIRD REGULARLY SCHEDULED TREATMENT SESSION → <u>NOT ELIGIBLE.*)</u>

4. Is ***(child's name)*** currently living with you? ____ Yes ____ No
   (IF NO:) Where is s/he living?
   (IF CHILD IS CURRENTLY LIVING IN A RESIDENTIAL TREATMENT CENTER OR AN INSTITUTION → <u>NOT ELIGIBLE</u>.*)

   (If child is living with another family:) Will you be the person responsible for getting ***(child's name)*** to mental health services? ____ Yes ____ No
   (IF NO → <u>NOT ELIGIBLE</u>.*)

OK. Your family fits the criteria to be in this project. Let's go ahead and schedule a time I can see you. Would you like me to come to your home to do the interview?

****(WHEN A CHILD IS NOT ELIGIBLE:)***
I am sorry, but we are including only children who ____***(<u>criteria not met.</u>)***____. Thank you for your time.

(If the person is upset about not being eligible, explain that the research project is limited to children who have certain characteristics. Remind the person that the child's/family's mental health services will be unaffected. If they continue to be upset, let them know you will give their name and phone number to the Project Manager, who will call them to discuss the situation. <u>Remember</u> to call Debi with this information.)

[If you contact a Spanish-speaking person, read him/her the following: Yo no hablo español. Una persona que habla español le volverá a llamar.]

FAMILY CONNECTIONS PROJECT
SCRIPT FOR INITIAL TELEPHONE CONTACT
(FOLLOW-UP INTERVIEW -- INTERVENTION)

Hello. My name is _____. I am with Portland State University and am working on the research project called the Family Connections Project. It's the project that _____, your Family Associate, is a part of. Do you remember this project? (If the respondent does not know what you are talking about, provide information as necessary to help her/him recall the project.)

I am calling because it's time to schedule the second interview for the project. You may remember doing the first interview and filling-out some forms. This second interview is very similar, except that I will be asking you questions about the mental health services **(child's name)** received, how satisfied you were with those services and any problems you may have experienced. I will also ask you about the Family Associate services you received and about any changes in your family circumstances that have occurred since the first interview. Like before, we will be paying you $25 for doing this interview.

Before we schedule a time to meet, do you have any questions about doing this interview? (Respond to any questions the respondent may have. If the respondent says s/he does not want to do the interview, discuss her/his concerns, remind her/him of confidentiality, and reduce any fears. Bottom Line: Encourage, But Do Not Force The Respondent To Do The Interview.)

Let's go ahead and schedule a time I can see you. Would you like me to come to your home to do the interview? (Verify the information you have on the Notification of Follow-Up Interview form, especially their home address.)

* * * * * * *

Following the telephone call, prepare the assessment materials for the interview.

FAMILY CONNECTIONS PROJECT
SCRIPT FOR INITIAL TELEPHONE CONTACT
(FOLLOW-UP INTERVIEW -- COMPARISON)

Hello. My name is _____. I am with Portland State University and am working on the research project called the Family Connections Project. I interviewed you 3 to 4 months ago for this research project about children's mental health services. Do you remember this project? (If the respondent does not know what you are talking about, provide information as necessary to help her/him recall the project.)

I am calling because it's time to schedule the second interview for the project. You may remember that the first interview involved me asking you a number of questions and you filling-out some forms. This second interview is very similar, except that I will be asking you questions about the mental health services **(child's name)** received, how satisfied you were with those services and any problems you may have experienced. I will also ask you about any changes in your family circumstances that have occurred since the first interview. Like before, we will be paying you $25 for doing this interview.

Before we schedule a time to meet, do you have any questions about doing this interview? (Respond to any questions the respondent may have. If the respondent says s/he does not want to do the interview, discuss her/his concerns, remind her/him of confidentiality, and reduce any fears. Bottom Line: Encourage, But Do Not Force The Respondent To Do The Interview.)

Let's go ahead and schedule a time I can see you. Would you like me to come to your home to do the interview? (Verify the information you have on the Notification of Follow-Up Interview form, especially their home address.)

* * * * * * *

Following the telephone call, prepare the assessment materials for the interview.

APPENDIX F

Informed Consent Form
(Used for Both Groups)
(English and Spanish Versions)

FAMILY CONNECTIONS PROJECT

INITIAL INTERVIEW

Family ID#:	Date:	Interviewer:

[1-6] [7-12]

INTRODUCTION

When we first talked over the phone, I explained a little bit about the research project. Before we begin the interview, I would like to give you more information about the project and have you read a Consent form. This form briefly describes the Family Connections Project and your role in that project. I will then ask you to sign the Consent form which means you agree to be a part of the Family Connections Project. We have three options for you. You can read the Consent form in English, or we have it in Spanish, or I could read it to you. Which would you prefer? I will answer any questions you have about the project.

(Hand the Informed Consent form to the respondent. Give a brief overview of the project as you hand them the form. To provide this brief overview, you may want to review the Parent Flyer with them. Do you have any questions? **(Make sure you review the exceptions to confidentiality with the respondent.)** Please sign and date the form at the bottom to show that you agree to be a part of the project. **(Give the respondent the pink copy.)** This copy is for you to keep.

During this interview, I will be asking you questions about the child who has been referred for mental health services, your household and family, and any mental health service experiences you and your family have had. I will also be asking you about what it was like to have a child referred for mental health services. This information will help us learn more about how to help children and families get started in mental health services. Since your time is valuable, the Regional Research Institute will pay you $25 for each interview you complete. This first interview will last 1 to 1-1/2 hours. The interview in 3-4 months will last a little longer.

I will be writing down your answers during the interview. At times it may seem strange that I am writing and not looking at you when you talk. This is not because I am not interested in what you have to say. I want to be sure I write exactly what you say. When I am done asking you some questions, I will give you some forms to fill-out. We can stop the interview at any time to take a break if you wish. You have the right to skip any of the questions I ask you. Please take your time answering the questions. We want you to give your most honest opinions. Do you have any questions about the research or the interview before we begin?

I WOULD LIKE TO BEGIN BY ASKING YOU QUESTIONS ABOUT (child's name), YOU, AND YOUR HOUSEHOLD. THIS INFORMATION WILL HELP US UNDERSTAND HOW (child's name) CURRENT SITUATION AND FAMILY CIRCUMSTANCES MAY INFLUENCE HER/HIS MENTAL HEALTH SERVICES. THIS INFORMATION WILL BE USED FOR RESEARCH PURPOSES ONLY AND WILL NOT BE SHARED WITH ANY OTHER PERSON OR AGENCY.

Respondent's FIRST name: _____ Child's FIRST name: _____

1. What is **(child's name)** sex? ____ Female$_1$ ____ Male$_2$ [13]

2. What is **her/his** date of birth? __ __ /__ __ /__ __ **(mo, day, yr)** [14-19]

3. What is **her/his** race? **(List term used by respondent following general category)**

___ African-American$_1$: _____

___ American Indian or Alaskan Native$_2$: _____

___ Asian or Pacific Islander$_3$: _____

___ Hispanic$_4$: _____

___ White$_5$: _____

___ Other$_6$: _____

(If more than one race given, use "2" for second race) [20] [21]

4. Is **(child's name)** currently enrolled in school, including home school?

___ **YES$_1$** [22]

4a. **(If YES, ask):** What is her/his current grade in school? _____ [23-24]

4b. **(If YES, ask):** Does **(child's name)** have an IEP (Individualized Education Plan)? An IEP looks like this **(show example)**.

___ YES$_1$ ___ DON'T KNOW$_3$ **(after adequate probing; Go to #5)** [25]

___ NO$_2$ **(Go to #5)**

→ **(If has IEP, ask):** What is the disabling condition s/he has an IEP for?

_____ [26-31]

→ **(If has IEP, ask):** What services is s/he receiving because of the IEP?

_____ [32-37]

(Go to #5)

___**NO$_2$** 4c. **(If NO, ask):** Why is s/he not enrolled in school? **(primary reason)**

___ too young$_1$ ___ between schools$_4$

___ dropped out$_2$ ___ summer vacation$_5$ **(ask #4d and #4e)**

___ expelled$_3$ ___ other$_6$: _____ [38]

4d. **(If NO, ask):** What was the last grade s/he completed? _____ [39-40]

(If on SUMMER VACATION, Go to #4e; otherwise Go to #5)

4e. **(If on SUM. VAC., ask):** Did **(child's name)** have an IEP (Individualized Education Plan) at the end of the last school year? An IEP looks like this **(show example)**.

___ YES$_1$ ___ NO$_2$ **(Go to #5)** ___ DON'T KNOW$_3$ **(after adequate probing; Go to #5)**

→ **(If had IEP, ask):** What is the disabling condition s/he had an IEP for?

_____

→ **(If had IEP, ask):** What services was s/he receiving because of the IEP?

_____

INFORMED CONSENT

I, _____, agree to take part in the Family Connections Project, a research project run by the Regional Research Institute for Human Services at Portland State University. I understand that the project is studying better ways of making mental health services available to children and families. My part in the study involves an interview now and another interview in three or four months. I will let the research staff know if I move so they can find me for the second interview. I understand that a different person may call me for the second interview. I will receive $25 for each interview. I do not expect any other direct benefit from participation in the study.

_____ has offered to answer any questions about the study. I understand that the research staff will have access to my file at the County and State Mental Health Departments. I understand that all information about me and my family will be confidential, except the following information which by law must be reported to the proper authorities:

(1) Information subpoenaed by a court of law (that is, demanded by a court of law).

(2) Suspected cases of abuse or neglect under Oregon state law. In other words, recent harm to a child will be reported.

(3) Information that individuals intend to harm themselves or others.

My name or identity will not be used in reports or for public discussion purposes. I may withdraw at any time from participation in this study without affecting the mental health services I or my family will receive.

I have read and understand this information and agree to participate in the Family Connections Project.

DATE _____ **SIGNATURE** _____

For questions or concerns about the research, please contact Nancy Koroloff or Debi Elliott at the Regional Research Institute for Human Services at Portland State University, 725-4040 or 1-800-547-8887, Ext. 4040.

For concerns about your treatment as a research participant, you may phone the Chairperson of the Human Subjects Research Review Committee, Portland State University, 725-3417.

CONSENTIMIENTO INFORMADO

Yo, _____, acuerdo participar en el "Family Connections Project" (proyecto de conexiones familiares), un proyecto investigativo dirigido por el "Regional Research Institute for Human Services" (instituto regional de investigaciones para servicios humanos) en la "Portland State University" (universidad estatal de Portland). Entiendo que el proyecto estudia mejores maneras de hacer los servicios de salud mental disponibles a niños y familias. Como mi parte en el estudio me corresponde una entrevista ahora y otra entrevista en tres o cuatro meses. Les informaré al personal de la investigación si me mudo para que me puedan localizar para la segunda entrevista. Recibiré $25 por cada entrevista. Yo no espero ningún otro beneficio directo por mi participación en el estudio.

_____ ha ofrecido contestar cualquier pregunta sobre el estudio. Entiendo que el personal de la investigación tendrá acceso a mi expediente en los "County y State Mental Health Departments" (departamentos de salud mental de condado y estatal). Entiendo que toda información tocante a mí y a mi familia será confidencial, excepto la información siguiente que por ley se tiene que reportar a las autoridades apropiadas:

1) Información emplazada por una corte de ley (o sea la que se exige por una corte de ley).

2) Sospechados casos de abuso o negligencia bajo las leyes estatales de Oregon. O sea, se reportarán daños recientes a un niño.

3) Información que individuos pretenden dañar a sí mismo ó a otros.

Ni mi nombre ni mi identidad se usará en informes ni con fines de discusión pública. Puedo retirar mi participación en el estudio en cualquier momento sin afectar el servicio de salud mental que yo o mi familia recibiremos.

He leído y entendido ésta información y acuerdo participar en el "Family Connections Project."

FECHA_____ FIRMA_____

Para hacer preguntas o aclarar dudas sobre la investigación, favor de comunicarse con Nancy Koroloff o Debi Elliott en el "Regional Research Institute" (instituto regional de investigaciones) en la "Portland State University" (universidad estatal de Portland) al 725-4040 o 1-800-547-8887 extensión 4040.

Para aclarar dudas sobre su tratamiento como participante de investigación, puede llamar a la persona encargada (chairperson) de la "Human Subjects Research Review Committee" (comité de revisión de investigaciones con sujetos humanos) de Portland State University, al 725-3417.

APPENDIX G

Initial Interview
(Used for Both Groups)

Follow-Up Interviews
(Intervention and Comparison Group Versions)

5. Who currently has legal custody of **(child's name)**?

___ I do$_1$ ___ The state (CSD)$_2$ ___ Other$_3$: _____ [41]

6. I am aware that **(child's name)** has a medical card. How does s/he qualify for a medical card? **(primary reason)**

___ Foster care$_1$ ___ Child's disability$_3$

___ Low income$_2$ ___ Other$_4$ _____ [42]

7. How are you related to **(child's name)**?

___ Birth Mother$_1$ ___ Stepfather$_4$ ___ Adoptive Mother$_7$ ___ Grandfather$_{10}$

___ Birth Father$_2$ ___ Foster Mother$_5$ ___ Adoptive Father$_8$ ___ Other$_{11}$:_____

___ Stepmother$_3$ ___ Foster Father$_6$ ___ Grandmother$_9$ _____ [43-44]

7a. **(If respondent is anything other than a birth parent ask)**: How long has s/he lived with you?

_____ Years _____ Months _____ Since Birth [45-48]

8. What is your age? _____ years [49-50]

9. What is your race? **(List term used by respondent following general category)**

___ African-American$_1$: _____

___ American Indian or Alaskan Native$_2$: _____

___ Asian or Pacific Islander$_3$: _____

___ Hispanic$_4$: _____

___ White$_5$: _____

___ Other$_6$: _____ [51]

(If more than one race given use "2" for second race) [52]

10. To get a sense for the caregiving responsibility you have, we would like to know <u>the number</u> of people living in your home and how many of those people you have to spend time taking care of. We do not need to know <u>who</u> lives with you. Please tell me just the <u>AGES</u> of <u>all</u> the people in your home <u>other than</u> you and **(child's name)**.

Person	Age	Care	Person	Age	Care
#1	____[53-54]	____[65]	#4	____[59-60]	____[68]
#2	____[55-56]	____[66]	#5	____[61-62]	____[69]
#3	____[57-58]	____[67]	#6	____[63-64]	____[70]

10a. **(If any teens [13 years & up] or adults are listed above, ask)**:

Do any of the older children/adults who are living with you require <u>extra</u> care from <u>you</u> because they have a disability, for example, a physical handicap, a chronic illness, a developmental handicap, or a serious emotional handicap?

(Put a ✔ in the "Care" column by the people identified as dependent.)

11. Do you have someone who shares daily parenting/caregiving responsibilities with you, such as a family member, partner, spouse or ex-spouse, friend, etc.? ___ Yes_1 ___ No_2 [71]

11a. **(If YES, ask):** What is their relationship to you? **(primary person)**

___ $Spouse/Partner_1$ ___ $Multiple\ Relatives_4$ ___ $Friend(s)_7$
___ $Parent_2$ ___ $Sibling_5$ ___ $Babysitter_8$
___ $Other\ Relative_3$ ___ $Boy/Girlfriend_6$ ___ $Other_9$: _____ [72]

NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT YOUR FINANCIAL RESOURCES. THIS INFORMATION IS CONFIDENTIAL AND WILL HELP US UNDERSTAND HOW A FAMILY'S RESOURCES MAY INFLUENCE MENTAL HEALTH SERVICES. THIS INFORMATION WILL BE USED FOR RESEARCH PURPOSES ONLY AND WILL NOT BE GIVEN TO ANY OTHER PERSON OR AGENCY.

12. Are you employed?

____ **YES_1** → What is your job?_____ [73][74]

(Go to #13)

____ **NO_2 (Go to #13)**

____ **$RETIRED_3$** → What was your job?_____

13. What is your highest level of education?

___ $Less\ than\ 7th\ grade_1$ ___ $Partial\ college\ (at\ least\ 1\ year)\ or\ specialized\ training_5$
___ $7th,\ 8th,\ or\ 9th\ grade_2$
___ $10th\ or\ 11th\ grade_3$ ___ $Standard\ college\ or\ university\ degree_6$
___ $High\ school\ diploma_4$ ___ $Graduate\ school\ or\ graduate\ degree_7$ [75]

WOULD LIKE TO ASK YOU QUESTIONS ABOUT *(child's name)* MENTAL HEALTH HISTORY.

21. FIRST, I WOULD LIKE TO KNOW WHAT TYPES OF MENTAL HEALTH SERVICES, IF ANY, *(child's name)* HAS RECEIVED. I WILL GO THROUGH A LIST OF SERVICE TYPES AND ASK YOU SOME QUESTIONS ABOUT EACH ONE.

	Is s/he CURRENTLY receiving ____?	**(If yes for CURRENT services, ask):**		In the PAST, has s/he ever received ___?	**(If yes for PAST services, ask): *[most recent service only]***
Outpatient therapy or counseling?	___Yes$_1$ ___No$_2$ [111]	How long has it been going on?_____ [112]		___Yes$_1$ ___No$_2$ [123]	How long ago did it end?_____ [124-126] How long did it last?_____ [127-128]
Counseling or group therapy at school?	___Yes$_1$ ___No$_2$ [113]	How long has it been going on?_____ [114]		___Yes$_1$ ___No$_2$ [129]	How long ago did it end?_____ [130-132] How long did it last?_____ [133-134]
Day treatment?	___Yes$_1$ ___No$_2$ [115]	How long has it been going on?_____ [116]		___Yes$_1$ ___No$_2$ [135]	How long ago did it end?_____ [136-138] How long did it last?_____ [139-140]
Residential treatment?	___Yes$_1$ ___No$_2$ [117]	How long has it been going on?_____ [118]		___Yes$_1$ ___No$_2$ [141]	How long ago did it end?_____ [142-144] How long did it last?_____ [145-146]
Therapeutic foster care?	___Yes$_1$ ___No$_2$ [119]	How long has it been going on?_____ [120]		___Yes$_1$ ___No$_2$ [147]	How long ago did it end?_____ [148-150] How long did it last?_____ [151-152]
Psychiatric hospitalization?	___Yes$_1$ ___No$_2$ [121]	How long has it been going on?_____ [122]		___Yes$_1$ ___No$_2$ [153]	How long ago did it end?_____ [154-156] How long did it last?_____ [157-158]

*** * * (If all the answers are "No", then Go to #25.) * * ***

22. **(If YES for any item in #21, hand the CHOICES card, ask:)** Looking at List A on this Choices card, generally, how have you felt about the mental health services **(child's name)** received? **(Circle their choice.)**

1	2	3	4	5	
All Good	Mostly Good, Some Bad	Half Good, Half Bad	Mostly Bad, Some Good	All Bad	[159]

23. **(If YES for any item in #21, ask):** While **(child's name)** was receiving those mental health services, were you ever given a name or diagnosis for **(her/his)** condition?

___ **YES**, ___ **NO** **(Go to #24)** [160]

(If yes, ask): What is the most current name or diagnosis for your child's condition? **(Check all that apply.)**

___ Don't know/Can't recall [161]
___ Adjustment Disorder [162]
___ Anxiety Disorder [163]
___ Attachment Disorder [164]
___ Attention Deficit Hyperactivity Disorder [165]
___ Autistic Disorder [166]
___ Avoidant Disorder [167]
___ Bipolar Disorder (Manic-Depression) [168]
___ Childhood Depression [169]
___ Conduct Disorder [170]
___ Developmental Disorder (Mental Retardation) [171]
___ Eating Disorder (Anorexia, Bulimia, Obesity) [172]
___ Enuresis/Encopresis [173]
___ Learning Disability [174]
___ Obsessive Compulsive Disorder [175]
___ Oppositional Disorder [176]
___ Phobia [177]
___ Post Traumatic Stress Disorder (PTSD) [178]
___ Schizophrenia [179]
___ Substance Abuse/Dependence [180]
___ Tourette's Syndrome [181]
___ Other: _____ [182]

14. What is your current marital status or living arrangement?

___ **SINGLE$_1$** **(If SINGLE, ask):** Have you ever been married? ___YES ___NO **(Go to #15)** [76]

→ **(If YES, determine whether DIVORCED or WIDOWED, ask appropriate questions below)**

___ **MARRIED or LIVING AS MARRIED$_2$**

(If MARRIED, ask): Is your spouse/partner employed?

___ YES$_1$ ___ NO$_2$ **(Go to #15)** ___ RETIRED$_3$ [77]

→ **(If spouse/partner Employed or Retired, ask):**

What is/was your spouse/partner's job? _____ [78]

→ **(If spouse/partner Employed or Retired, ask):**

What is your spouse's/partner's highest level of education?

___ Less than 7th grade$_1$
___ 7th, 8th, or 9th grade$_2$
___ 10th or 11th grade$_3$
___ High school diploma$_4$
___ Partial college (at least 1 year) or specialized training/trade school$_5$
___ Standard college or university degree$_6$
___ Graduate school or graduate degree$_7$ [79]

(Go to #15)

___ **DIVORCED$_3$**
___ **SEPARATED$_4$**

(If DIVORCED or SEPARATED, ask): Is your (ex-) spouse employed?

___YES$_1$ ___ NO$_2$ **(Go to #15)** ___ RETIRED$_3$

→ **(If (ex-)spouse Employed or Retired, ask):**

What is/was your (ex-)spouse's job? _____

→ **(If (ex-)spouse Employed or Retired, ask):**

What is your (ex-)spouse's highest level of education?

___ Less than 7th grade$_1$
___ 7th, 8th, or 9th grade$_2$
___ 10th or 11th grade$_3$
___ High school diploma$_4$
___ Partial college (at least 1 year) or specialized training/trade school$_5$
___ Standard college or university degree$_6$
___ Graduate school or graduate degree$_7$

(Go to #15)

___ **WIDOWED$_5$**

(If WIDOWED, ask): Was your spouse employed?

___YES$_1$ ___ NO$_2$ **(Go to #15)** ___ RETIRED$_3$

→ **(If late spouse Employed or Retired, ask):**

What was your spouse's job? _____

→ **(If late spouse Employed or Retired, ask):**

What was your spouse's highest level of education?

___ Less than 7th grade$_1$
___ 7th, 8th, or 9th grade$_2$
___ 10th or 11th grade$_3$
___ High school diploma$_4$
___ Partial college (at least 1 year) or specialized training/trade school$_5$
___ Standard college or university degree$_6$
___ Graduate school or graduate degree$_7$

(Go to #15)

[80-81]

15. What are the sources of income in your household? **(Check all that apply.)**

___ Employment$_1$ [82]
___ Welfare/AFS$_2$ [83]
___ Social Security$_3$ [84]
___ AFDC (Aid to Families with Dependent Children)$_4$ [85]
___ Foster Care Support$_5$ [86]
___ Child Support$_6$ [87]
___ Supplemental Security Income (SSI)$_7$ [88]
___ Pension/retirement funds$_8$ [89]
___ Alimony$_9$ [90]
___ Deceased spouse's estate$_{10}$ [91]
___ Other$_{11}$: _____ [92]

15a. **(If more than one source is given, ask):** Which is the primary source of income? **(Circle one above.)** [93-94]

16. **(Hand the ANNUAL INCOME card.)** Listed on this card are some income levels. Please read me the letter next to the annual income before taxes for your household. ***(Check one)***

a. ___ Under $10,000$_1$
b. ___ $10,000 to $14,999$_2$
c. ___ $15,000 to $19,999$_3$
d. ___ $20,000 to $24,999$_4$
e. ___ $25,000 to $34,999$_5$
f. ___ $35,000 to $44,999$_6$
g. ___ $45,000 to $54,999$_7$
h. ___ $55,000 and up$_8$ [95]

NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT WHERE YOU LIVE AND HOW FAR YOU LIVE FROM SOME MAJOR LANDMARKS.

17. What city/town do you list as your address? _____ [96]

18. Do you live within this city/town's limits?

___ **YES$_1$ (Go to #19)** [97]

___ **NO$_2$** ___ **DON'T KNOW$_3$** **(If NO or DON'T KNOW, ask):** How many miles from this city/town do you live?

_____Miles. [98-99]

19. How many miles do you live from:

_____ (miles) the nearest Post Office [100-101]
_____ (miles) the nearest Public Library [102-103]
_____ (miles) the nearest hospital [104-105]
_____ (miles) your child's school [106-107]
_____ (miles) the mental health office that you will be going to [108-109]
(If office not chosen yet, complete later)

20. Are there any times of the year when you cannot travel? ___ Yes$_1$ ___ No$_2$ **(Go to #21)** [110]

20a. **(If yes, ask):** When, for how long, and why can't you travel?: _____

_____

30. When **(child's name)** had his/her Medicheck, were you given a form by the doctor/nurse recommending that **(child's name)** receive mental health services? It should look like this **(show example)**.

___ **YES$_1$** **(If YES, ask):** What were you told to do with it? [203]

_____

(Go to #31)

___ **NO$_2$** **(If NO, ask):** Were you given anything else in writing?

___ Yes$_1$ ___ No$_2$ **(Go to #31)** [204]

→ **(If given something else in writing, ask):** What was it?

_____ [205]

→ **(If given something else in writing, ask):** What were you told to do with it?

_____

31. Have you received something in the mail from the mental health office?

___ **YES$_1$** ___ **NO$_2$** [206]

COMMENTS: _____

_____

_____

32. Did you receive a phone call from the mental health office?

___ **YES$_1$** ___ **NO$_2$** [207]

COMMENTS: _____

_____

_____

33. Did you call the mental health office?

___ **YES$_1$** ___ **NO$_2$** [208]

COMMENTS: _____

_____

_____

34. Has an appointment been made with the mental health office for **(child's name)**?

____ **YES$_1$** **(If YES, ask:)** When is your appointment?_____ [209]

(If YES, ask): Was it difficult to get? ___Yes$_1$ ___No$_2$ **(Go to #35)** [210]

→ **(If it was difficult, ask):** In what way was it difficult? _____

_____

____ **NO$_2$**

NOW THAT YOU HAVE DESCRIBED THE PROCESS YOU WENT THROUGH TO GET (child's name) INTO MENTAL HEALTH SERVICES, I WOULD LIKE TO ASK YOU WHAT YOU THOUGHT ABOUT THAT EXPERIENCE:

35. **(Hand CHOICES card):** Looking at LIST B on the CHOICES card, how easy or difficult do you think the process was for you? **(Circle their choice.)**

1	2	3	4	5
Very Easy	Somewhat Easy	Just Fine	Somewhat Difficult	Very Difficult

[211]

COMMENTS:_____

_____

36. Looking at LIST C on the CHOICES card, how do you feel about how long that process lasted? **(Circle their choice.)**

1	2	3	4
Way too Slow	Kinda Slow, But OK	Just About Right	Faster Than I Expected

[212]

COMMENTS:_____

_____

37. About how long did the whole process take, from the point when you first started trying to get Mental Health services for **(child's name)** to the point when you got an appointment (**OR** now if no appointment has been made)?

_____ Weeks _____ Months [213-214]

(If YES for any item in #21): NOW, I AM GOING TO READ A LIST OF THINGS THAT CAN GET IN A PARENT'S WAY OF GETTING THEIR CHILD TO TREATMENT, RESULTING IN MISSED APPOINTMENTS, NOT STARTING TREATMENT, OR ENDING TREATMENT BEFORE IT'S DONE.

24. Have any of these things ever gotten in the way of you being able to get your child to mental health services?

(Read each item; check all that apply)

___ Transportation problems [183]
___ Child care problems [184]
___ Too far to travel [185]
___ Could not afford [186]
___ Time conflict [187]
___ Process was too confusing [188]
___ Disruptive to regular family routine [189]
___ Did not think child needed mental health services [190]
___ Did not think the mental health services were helping [191]
___ Disagreed with diagnosis or treatment approach [192]
___ Child refused to be in treatment [193]
___ Did not feel comfortable being associated with mental health services [194]
___ Did not like therapist/counselor/ social worker/program [195]
___ Other: _____ [196]
___ NONE APPLY

25. Have you ever participated in mental health services with any other child(ren)?
___Yes$_1$ ___ No$_2$ **(Go to #26)** [197]

25a. **(If yes, [hand CHOICES card], ask):** Looking at List A on the CHOICES card, generally, how have you felt about the mental health services she/he/they received? **(Circle their choice.)**

1	2	3	4	5
All Good	Mostly Good, Some Bad	Half Good, Half Bad	Mostly Bad, Some Good	All Bad

[198]

26. **(If any child has received mental health services, ask):** Were you ever involved with a parent support group when any of your children were receiving mental health services?
___ Yes$_1$ ___ No$_2$ [199]

27. Have you ever received any mental health services? ___Yes$_1$ ___No$_2$ **(Go to #28)** [200]

27a. **(If yes, hand CHOICES card, ask):** Looking at List A on the CHOICES card, generally, how have you felt about the mental health services you received? **(Circle their choice.)**

1	2	3	4	5
All Good	Mostly Good, Some Bad	Half Good, Half Bad	Mostly Bad, Some Good	All Bad

[201]

(CHILD'S NAME) HAS BEEN REFERRED FOR MENTAL HEALTH SERVICES. SOMETIMES A PARENT HAS TO GO THROUGH MANY DIFFERENT STEPS TO GET FROM WANTING SERVICES TO ACTUALLY GETTING SERVICES. IN YOUR SITUATION, WE WOULD LIKE TO KNOW HOW THIS PROCESS HAPPENED.

ONE OF THE STEPS WE KNOW MAY OCCUR IS FOR A CHILD TO HAVE A MEDICHECK. THAT A VISIT WITH A MEDICAL PROFESSIONAL WHO RECOMMENDS THAT A CHILD RECEIVE MENTAL HEALTH SERVICES.

28. Who did the Medicheck for **(child's name)**?
(If the respondent says "The clinic", "The doctor", "The nurse", or gives you a doctor's/nurse name, ask if the clinic or the doctor/nurse is part of Public Health/Health Dept.)
___ Private physician$_1$
___ Public Health/Health Dept.$_2$
___ School Nurse$_3$
___ Other$_4$: _____
___ No Medicheck done (explain below)$_5$

29. Who suggested that you get the Medicheck for **(child's name)**?

(Ask as many questions as necessary to trace back to the beginning of this process of wanting/needing mental health services. Describe any additional "system-related" steps below.)

38. Looking at LIST D on the CHOICES card, how satisfied are you with how you were treated throughout the process when **(child's name)** was being referred for mental health services? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[215]

COMMENTS: _____

_____

I AM GOING TO READ YOU A LIST OF THINGS THAT SOMETIMES GET IN THE WAY OF TAKING A CHILD TO TREATMENT, RESULTING IN MISSED APPOINTMENTS, NOT STARTING TREATMENT, OR ENDING TREATMENT BEFORE IT IS DONE.

39. I would like you to tell me if it is possible that any of the following things may get in your way. **(Read each item; check all that apply.)**

___ Transportation problems [216]
___ Child care problems [217]
___ Being too far to travel [218]
___ Time conflict [219]
___ Child refusing to be in treatment [220]
___ Being confused about next step [221]
___ Being disruptive to regular family routine [222]
___ Deciding child does not need mental health services [223]
___ Not feeling the mental health services are helping [224]
___ Not feeling comfortable being associated with mental health services [225]
___ Disagreeing with diagnosis or treatment approach [226]
___ Not liking therapist/counselor/social worker/ program [227]
___ Other: _____ [228]
___ NONE APPLY

40. About how long do you think **(child's name)** will be involved with mental health services? **(If the respondent hesitates, encourage her/him to guess.)**

_____ Months _____ Years [229-230]

41. In closing, I would like to ask if there is anything you would like to add or comment on, or if you have any additional reactions to having **(child's name)** referred for mental health services.

_____

_____

_____

_____

_____

_____

(CONTINUE ON BACK IF NECESSARY)

INTRODUCING THE QUESTIONNAIRES

We have finished the first part of this interview. Now I would like to ask you to fill out a few questionnaires. It should take about 20 to 40 minutes. Again, we have three options for you. You can read the questionnaires in English, or we have them in Spanish, or I could read them to you. Which would you prefer?

(Give a brief overview for each of the questionnaires. Point out the parts of the CBCL that are not completed. Emphasize that the questionnaires are double-sided. When s/he is done filling them out, say): Did you have any questions about any of the items?

(Respond to any questions s/he may have. If help is needed to understand an item, do your best to rephrase the item without changing the meaning of the item or providing the respondent with any additional information. Review each questionnaire to make sure all of the items were answered and say): I just need to quickly glance through these to make sure we filled everything out.

CLOSING SUMMARY FOR INITIAL INTERVIEW

(If the respondent is unable to complete the questionnaires, give her/him the option of keeping them to finish. Schedule a time to pick them up within the next couple of days. Explain that s/he will receive the $25 when the forms are completed and picked-up. Thank the respondent for her/his time and help thus far.)

(For those who complete all of the questionnaires, say): Thank you very much for participating in this interview. You have helped us a lot and we appreciate your time. Here is your $25 check. Please sign this receipt to show that you have received the $25 for this initial interview.

I will be contacting you in about three to four months to schedule a follow-up interview. We will need to know if there are any changes in your name, address or telephone number. You can call Debi Elliott, the Project Manager, at the phone number listed on your copy of the consent form to tell her about any changes (or on the Parent Flyer). She can also answer any questions you may have about the interviews or the research project. In case we have any trouble getting in touch with you, is there someone we could call who would always know where you are living?

NAME: _____ RELATIONSHIP: _____

TELEPHONE NUMBERS: _____ (Home) _____ (Work)

Again, thank you for your time. I have enjoyed talking with you.

FAMILY CONNECTIONS PROJECT

FOLLOW-UP INTERVIEW -- INTERVENTION

FAMILY ID#:	TODAY'S DATE: FIRST INTERVIEW DATE:	INTERVIEWER:

[1-6] [7-12]

INTRODUCTION

As I mentioned on the phone, this is a follow-up to the interview you did about 3-4 months ago for the Family Connections Project. Before we begin, I would like to review the Consent form you signed before. As you recall, this form was the way for you to agree to be a part of this project and described the confidential nature of the information you give us. I would like you to review it. You can read it in English or in Spanish, or I can read it to you. Which would you prefer? When you are finished, I will answer any questions you have. **(Hand the copy of the Informed Consent form to the respondent.)** Do you have any questions? **(Make sure you remind the respondent about the exceptions to confidentiality.)**

During this interview, I will be asking you questions about **(child's name)**, the mental health services s/he received, how satisfied you were with those services and any problems you may have experienced. I will also ask you about the Family Associate services you received and about any changes in your family circumstances that have occurred since the first interview. This interview will last about 1 to 1-1/2 hours. Because your time is valuable, the Regional Research Institute will pay you $25 for this interview.

As in the first interview, I will be writing down your answers as you give them to me. At times it may seem strange that I am writing and not looking at you when you talk. This is not because I am not interested in what you have to say. I want to be sure I write exactly what you say. When I have finished asking you questions, I will give you some forms to fill-out. We can stop the interview at any time to take a break if you wish. You have the right to skip any of the questions I ask you. Please take your time answering the questions. We want you to give your most honest opinions.

Do you have any questions about the research or the interview before we begin?

I WOULD LIKE TO BEGIN BY ASKING YOU QUESTIONS ABOUT (child's name), YOU, AND YOUR HOUSEHOLD. THIS INFORMATION WILL HELP US UNDERSTAND HOW (child's name) CURRENT SITUATION AND FAMILY CIRCUMSTANCES MAY INFLUENCE HER/HIS MENTAL HEALTH SERVICES. THIS INFORMATION WILL BE USED FOR RESEARCH PURPOSES ONLY AND WILL NOT BE SHARED WITH ANY OTHER PERSON OR AGENCY.

Respondent's FIRST name: **Child's FIRST name:**

1. Is **(child's name)** currently living with you? ___ YES_1 **(Go to #2)** ___ NO_2 [13]
   (If NO, ask): Where is she/he living now? _____ [14]

2. Did **(child's name)** consistently live with you since the first interview?
   ___ YES_1 **(Go to #3)** ___ NO_2 [15]

   (If NO, ask): Where else has she/he lived? _____
   (If NO, ask): For how long? _____

3. Is **(child's name)** currently enrolled in school, including home school?

___ **YES_1** [16]

3a. **(If YES, ask):** What is her/his current grade in school? _____ [17-18]

3b. **(If YES, ask):** Does **(child's name)** have an IEP (Individualized Education Plan)? An IEP looks like this **(show example)**.
___ YES_1 ___ DON'T $KNOW_3$ **(after adequate probing; Go to #4)** [19]
___ NO_2 **(Go to #4)**
→ **(If has IEP, ask):** What is the disabling condition s/he has an IEP for?
_____ [20-25]
→ **(If has IEP, ask):** What services is s/he receiving because of the IEP?
_____ [26-31]
(Go to #5)

___**NO_2** 3c. **(If NO, ask):** Why is s/he not enrolled in school? **(primary reason)**
___ too $young_1$ ___ between $schools_4$
___ $dropped\ out_2$ ___ summer $vacation_5$ **(ask #3d and #3e)**
___ $expelled_3$ ___ $other_6$: _____ [32]

3d. **(If NO, ask):** What was the last grade s/he completed? _____ [33-34]
(If on SUMMER VACATION, Go to #3e; otherwise Go to #4)

3e. **(If on SUMMER VACATION, ask):** Did **(child's name)** have an IEP (Individualized Education Plan) at the end of the last school year? An IEP looks like this **(show example)**. ___ YES_1 ___ NO_2 **(Go to #4)** [35]
→ **(If had IEP, ask):** What is the disabling condition s/he had an IEP for?
_____ [36-41]
→ **(If had IEP, ask):** What services was s/he receiving because of the IEP?
_____ [42-47]

4. When you did the first interview, **(child's name)** had a Medical Card. Does she/he still have a Medical Card?

___ YES$_1$ **(Go to #5)** ___ NO$_2$ [48]

4a. **(If NO, ask):** Why doesn't she/he have a medical card anymore?

_____ [49]

5. As you may recall from the first interview, we wanted to get a sense for the caregiving responsibility you have. To do that, we asked you to tell us the number of people living in your home and how many of those people you had to spend time taking care of. Since the first interview, have there been any changes in the number of people who are living in your home?

___ YES$_1$ **(Ask #5a and #5b)** ___ NO$_2$ **(Go To #6)** [50]

(If the respondent is not sure of their response for the initial interview, ask #5a and #5b.)

5a. **(If YES, ask):** Please tell me the AGES of all the people in your home other than you and **(child's name)**.

Person	Age	Care	Person	Age	Care
#1	____[51-52]	____[53]	#4	____[60-61]	____[62]
#2	____[54-55]	____[56]	#5	____[63-64]	____[65]
#3	____[57-58]	____[59]	#6	____[66-67]	____[68]

___ **N/A: Respondent and Child are the ONLY people in the home. (Go To #6)**

5b. **(If any teens [13 years & up] or adults are listed, ask):** Do any of the teenagers/adults who are living with you require extra care from you because they have a disability, for example, a physical handicap, a chronic illness, a developmental handicap, or a serious emotional handicap? **(Put a ✔ in the "Care" column by the people identified as dependent.)**

6. Do you have someone who shares daily parenting/caregiving responsibilities with you?

___ YES$_1$ ___ NO$_2$ **(Go To #7)** [69]

6a. **(If YES, ask):** What is their relationship to you? **(primary person)**

___ Spouse/Partner$_1$ ___ Multiple Relatives$_4$ ___ Friend(s)$_7$

___ Parent$_2$ ___ Sibling$_5$ ___ Babysitter$_8$

___ Other Relative$_3$ ___ Boy/Girlfriend$_6$ ___ Other$_9$: _____ [70]

7. Have you moved since the first interview? ___ YES_1 ___ NO_2 **(Go To #8)** [71]

7a. **(If MOVED, ask):** What city/town do you list as your address? _____ [72]

7b. **(If MOVED, ask):** Do you live within this city/town's limits?
___ YES_1 **(Go to #7c)** ___ NO_2 ___ DON'T $KNOW_3$ [73]

→ **(If NO or DON'T KNOW, ask):** How many miles from this city/town do you live?
_____Miles. [74-75]

7c. **(If MOVED, ask):** How many miles do you live from:

_____ (miles) the nearest Post Office [76-77]
_____ (miles) the nearest Public Library [78-79]
_____ (miles) the nearest hospital [80-81]
_____ (miles) **(child's name)** school [82-83]
_____ (miles) the mental health office **(child's name)** is/was going [84-85]

7d. **(If MOVED, ask):** Are there any times of the year when you cannot travel?
___ YES_1 ___ NO_2 **(Go to #8)** [86]

→ **(If YES, ask):** When, for how long, and why can't you travel?:
_____

8. Do you consider your family to be living in an area that is RURAL or URBAN **(circle one)**? [87]
COMMENTS: _____
_____

NOW I WOULD LIKE TO ASK YOU ABOUT THE MENTAL HEALTH SERVICES (CHILD'S NAME) HAS RECEIVED SINCE THE FIRST INTERVIEW.

9. Has **(child's name)** received any mental health services since the first interview for this project?

___ YES$_1$ **(Go to #10)** [88]

___ NO$_2$ **(If NO, ask):** I am going to read you a list of things that can get in a parent's way of getting their child to mental health services. Please tell me if any of these kept you from getting **(child's name)** started in mental health services.

(Read each item; check all that apply; record anecdotal information.)

___ Transportation problems [89]
___ Child care problems [90]
___ Was too far to travel [91]
___ Time conflict [92]
___ Child refused to be in treatment [93]
___ Confused about next step [94]
___ Would have been disruptive to regular family routine [95]
___ Decided child did not need mental health services [96]
___ Didn't think mental health services would help [97]
___ Didn't feel comfortable being associated with mental health services [98]
___ Didn't think mental health services would meet child's and/or your ethnic/cultural needs [99]
___ Thought it would conflict with child's and/or your religious beliefs or spirituality [100]
___ Didn't think anyone would speak child's and/or your language (includes sign language) [101]
___ Other: _____ [102]
___ NONE APPLY

(If barriers experienced, ask): Did your Family Associate help you deal with any of those problems? ___ YES$_1$ ___ NO$_2$ **(Go to #23)** ___ N/A$_3$ **(Explain below)** [103]

→ **(If YES, ask):** Which problem(s) and how did she help you?

_____

_____

_____

_____

_____

_____

(Go To #23)

10. A child will usually receive a mental health evaluation before treatment/counseling begins. The evaluation is done to identify the child's difficulties and decide what services are needed. Did **(child's name)** receive a mental health evaluation?

___ **YES$_1$** [104]

(If YES, ask): Were you given the results of that evaluation? ___ YES$_1$ ___ NO$_2$ [105]

→ **(If results were given, ask):**

Were you shown a copy of the written report? ___ YES$_1$ ___ NO$_2$ [106]

Did the therapist verbally review the results with you? ___ YES$_1$ ___ NO$_2$ [107]

___ **NO$_2$ (Go to #12)**

___ **DON'T KNOW$_3$ (Go to #12)**

11. **(Hand the CHOICES card):** Looking at LIST A on the CHOICES card, generally how satisfied were you with the mental health evaluation for **(child's name)**? **(Circle their choice.)**

1	2	3	4	5
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied

[108]

COMMENTS: _____

_____

12. Were you given a name or diagnosis for **(child's name)** condition or disorder?

___ **YES$_1$** [109]

(If YES, ask): What is the name or diagnosis you were given? **(Check all that apply.)**

___ Don't know/Can't recall [110]
___ Adjustment Disorder [111]
___ Anxiety Disorder [112]
___ Attachment Disorder [113]
___ Attention Deficit Hyperactivity Disorder (ADHD) [114]
___ Autistic Disorder [115]
___ Avoidant Disorder [116]
___ Bipolar Disorder (Manic-Depression) [117]
___ Childhood Depression [118]
___ Conduct Disorder [119]
___ Developmental Disorder (Mental Retardation) [120]
___ Eating Disorder (Anorexia, Bulimia, or Obesity) [121]
___ Enuresis/Encopresis [122]
___ Learning Disability [123]
___ Obsessive Compulsive Disorder [124]
___ Oppositional Disorder [125]
___ Phobia [126]
___ Post Traumatic Stress Disorder (PTSD) [127]
___ Schizophrenia [128]
___ Substance Abuse/Dependence [129]
___ Tourette's Syndrome [130]
___ Other: _____ [131]

___ **NO$_2$**

13. Other than a mental health evaluation, what type(s) of mental health services has **(child's name)** received? **(check all that apply)**

___ Individual therapy [132] ___ Family therapy [134]
___ Group therapy [133] ___ Day treatment [135]
___ Other:_____ [136]

14. How often do the scheduled appointments occur?
___ 1/week$_1$ ___ 1/two weeks$_2$ ___ 1/month$_3$
___ Other$_4$: _____ [137]

14a. Looking at List B on the CHOICES card, generally how do you feel about how often the appointments occur? **(circle their choice)**

1	2	3
Not Often Enough	Just Right	Too Often

[138]

COMMENTS: _____
_____
_____

15. How many mental health appointments has **(child's name)** attended?
(Encourage respondent to make her/his best guess. When necessary, show calendar to help respondent recall first appointment and count forward.)

_____ Appointments Attended [139-140]
_____ N/A; Child in Day Treatment (i.e., not attending isolated appointments)

16. Were there any scheduled appointments that **(child's name)** and/or you had to miss?

___ **YES**$_1$ [141]

(If YES, ask): How many appointments were missed? _____ [142]

(If YES, ask): Did any of those missed appointments occur while you were working with your Family Associate? ___ YES$_1$ ___ NO$_2$ [143]

→ **(If YES, ask):** How many? _____ [144]

(If YES, ask): I am going to read you a list of things that can get in a parent's way of getting their child to mental health appointments. Please tell me if any of these were reasons why **(child's name)** was unable to attend some of her/his mental health appointments. **(Read each item; check all that apply; record anecdotal information)**

___ Transportation problems [145]
___ Child care problems [146]
___ Was too far to travel [147]
___ Time conflict [148]
___ Child refused to attend treatment sessions [149]
___ Was disruptive to regular family routine [150]
___ Decided child did not need mental health services [151]
___ Didn't feel the mental health services were helping [152]
___ Didn't feel comfortable being associated with mental health services [153]
___ Didn't think mental health services were meeting child's and/or your ethnic/cultural needs [154]
___ Mental health services conflicted with child's and/or your religious beliefs or spirituality [155]
___ Mental health worker didn't speak child's and/or your language (includes sign language) [156]
___ Disagreed with diagnosis or treatment approach [157]
___ Didn't like therapist/counselor/social worker/program [158]
___ Other: _____ [159]
___ NONE APPLY **(Go to #17)**

(If barriers experienced, ask): Did your Family Associate help you deal with any of those problems? ___ YES$_1$ ___ NO$_2$ **(Go to #17)** ___ N/A$_3$ **(Explain below)** [160]

→ **(If YES, ask):** Which problem(s) and how did she help you?

_____

_____

_____

_____

_____

___ **NO**$_2$

17. Were the services **(child's name)** received the type you expected she/he would get?

___ YES_1 **(Go To #18)** ___ NO_2 [161]

17a. **(If NO, ask):** How have they been different?_____

_____

_____

18. Is **(child's name)** still receiving mental health services?

___ **YES_1** [162]

(If YES, ask): What type(s) of services is she/he receiving now? **(check all that apply)**

___ Individual therapy [163] ___ Family therapy [165] ___ Other:_____

___ Group therapy [164] ___ Day treatment [166] _____ [167]

(Go To #19)

___ **NO_2**

(If NO, ask): I am going to read you a list of things that can get in the way of a child continuing mental health services. Please tell me if any of these were reasons for **(child's name)** ENDING mental health services.

(Read each item; check all that apply; record anecdotal information.)

___ Therapist said treatment was completed [168]

___ Child was doing better, we chose to end treatment [169]

___ Transportation problems [170]

___ Child care problems [171]

___ Was too far to travel [172]

___ Time conflict [173]

___ Child refused to be in treatment [174]

___ Was disruptive to regular family routine [175]

___ Didn't feel the mental health services were helping [176]

___ Didn't feel comfortable being associated with mental health services [177]

___ Didn't think mental health services were meeting child's and/or your ethnic/cultural needs [178]

___ Mental health services conflicted with child's and/or your religious beliefs or spirituality [179]

___ Mental health worker didn't speak child's and/or your language (includes sign language) [180]

___ Didn't like therapist/counselor/social worker/program [181]

___ Disagreed with diagnosis or treatment approach [182]

___ Other: _____ [183]

___ NONE APPLY **(Go to #19)**

(If barriers experienced, ask): Did your Family Associate help you deal with any of those problems? ___ YES_1 ___ NO_2 **(Go to #19)** ___ N/A_3 **(Explain below)** [184]

→ **(If YES, ask):** Which problem(s) and how did she help you?

_____

_____

_____

_____

_____

19. **(Hand the CHOICES card):** Looking at List A on the CHOICES card, generally, how satisfied are you with the mental health services **(child's name)** has received? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[185]

COMMENTS: _____

_____

_____

20. Looking at LIST A, generally how satisfied are you with how you have been treated as a parent/caregiver during **(child's name)** mental health services? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[186]

COMMENTS: _____

_____

_____

21. Looking at LIST A, generally how satisfied are you with the therapist(s) or counselor(s) who provided the mental health services for **(child's name)**? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[187]

COMMENTS: _____

_____

_____

22. Looking at LIST A, generally how satisfied are you with the level of involvement you had in **(child's name)** mental health services? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[188]

COMMENTS: _____

_____

_____

23. Since the first interview for this project, have you participated in a parent support group?
___ YES_1 ___ NO_2 **(Go to #24)** [189]

(If YES, ask): Looking at LIST C on the CHOICES card, generally how do you feel about having participated in the parent support group?

1	2	3	4	5	
All Good	Mostly Good, Some Bad	Half Good, Half Bad	Mostly Bad, Some Good	All Bad	[190]

COMMENTS: _____

_____

_____

FAMILY ASSOCIATE SERVICES

I WANT TO ASK YOU SOME QUESTIONS ABOUT THE FAMILY ASSOCIATE WHO WORKED WITH YOU AFTER (CHILD'S NAME) WAS REFERRED FOR MENTAL HEALTH SERVICES. THE FAMILY ASSOCIATE WHO WORKED WITH YOU WAS _____. REMEMBER, THE FAMILY ASSOCIATE ROLE IS SOMETHING THAT WAS DEVELOPED FOR THIS RESEARCH PROJECT BECAUSE WE WANTED TO SEE IF THIS PERSON COULD BE HELPFUL TO PARENTS. NOW WE NEED TO KNOW WHAT YOU THOUGHT OF THE FAMILY ASSOCIATE AND HOW HELPFUL HER SERVICES WERE FOR YOU AND YOUR FAMILY.

WHATEVER YOU SAY ABOUT THE FAMILY ASSOCIATE WILL REMAIN PRIVATE. WHAT YOU AND OTHER FAMILIES SAY WILL BE GROUPED TOGETHER, SO THE FAMILY ASSOCIATES WON'T BE ABLE TO IDENTIFY WHO SAID IT. THE QUESTIONS WILL HELP US FIND OUT IF THE FAMILY ASSOCIATE SERVICES WERE HELPFUL AND THE BEST WAY TO PROVIDE THOSE SERVICES.

24. Before we begin this set of questions, let me make sure that you actually spent time working with the Family Associate who interviewed you about three to four months ago?

___ YES_1 **(Go to #25)** ___ NO_2 [191]

(If NO, ask): Why did you choose not to work with the Family Associate? _____

_____

_____

_____

(Go to #34)

25. Looking at List D on the CHOICES card, how clearly did your Family Associate explain what her job was and how she could help you? **(Circle their choice.)**

1	2	3	4	
Not At All	Slightly	Moderately	Very	[192]

COMMENTS: _____

_____

26. Looking at List A, how satisfied are you with how often your Family Associate visited or called you? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[193]

COMMENTS: _____

_____

27. Looking at List A, generally how satisfied are you with the way you and your Family Associate got along together? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[194]

COMMENTS: _____

_____

28. What was the most helpful thing the Family Associate did for you? _____

_____

_____

_____

29. What was the least helpful thing the Family Associate did for you? _____

_____

_____

_____

30. Was there anything else you wanted your Family Associate to do but she didn't or couldn't do?

___ YES_1 ___ NO_2 **(Go to #31)** [195]

30a. **(If YES, ask):** What was it? _____

_____

31. Looking at List D on the CHOICES card, when you were trying to get **(child's name)** started in mental health services, how helpful was your Family Associate? **(Circle their choice.)**

0	1	2	3	4	
N/A*	Not At All	Slightly	Moderately	Very	[196]

***N/A should be chosed only when families started services before the Family Associate began working with them.**

COMMENTS: _____

_____

32. Did you receive any money from the Family Associate or did she buy something for your family?

___ YES_1 ___ NO_2 **(Go to #33)** [197]

32a. **(If YES, ask):** Did the money or thing she bought make getting **(child's name)** to mental health services easier? ___ YES_1 ___ NO_2 [198]

Why/Why not? _____

_____

_____

33. What did you learn from working with the Family Associate that would be useful for other parents to know? _____

34. **I WOULD LIKE TO ASK YOU ONE LAST QUESTION. THIS IS ABOUT HOW YOUR FAMILY IS DOING NOW COMPARED TO OVER THE LAST FEW MONTHS.**

(Show respondent graph): This is a graph that will show how well your family was doing at two times in the past and right now. By "how well your family was doing" I mean, in general, how well your family was communicating, dealing with disagreements and solving problems. Looking at the graph, this line ranges from "Really Great" to "Not Great, But OK" to "Really Badly". We will be using that range to describe your family.

Let's start when you were first interviewed for this project on _____ **(See first page for date)**. Thinking back to that time, put an **X** on this line to show how well your family was doing.
(If necessary, help the respondent decide where to put the X. Make sure you do NOT decide for them, but rather just help them understand and manage the task.) [199]

Now, thinking back to:

a) **(For respondents who worked with FA):** when your Family Associate STOPPED working with you,

-OR-

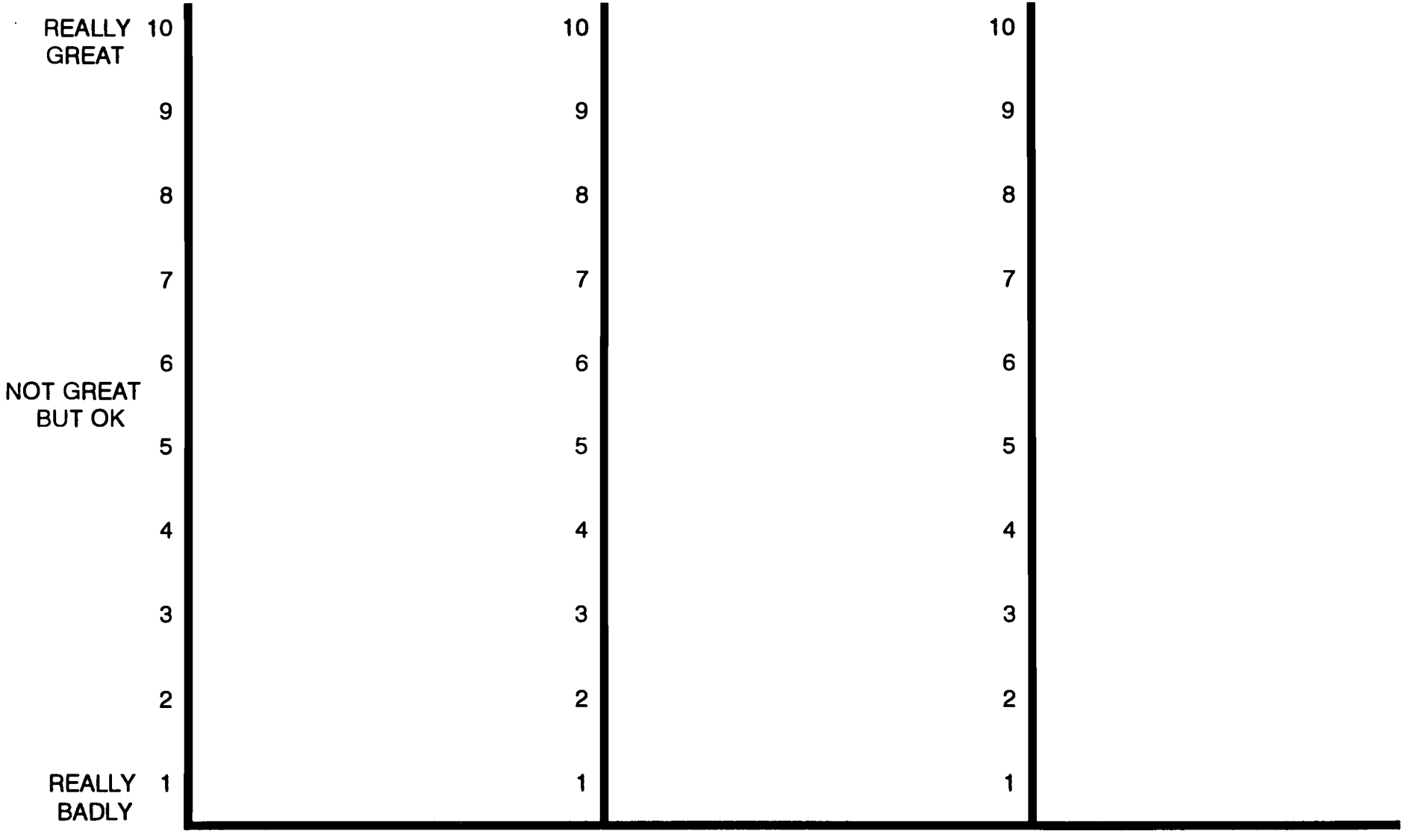
b) **(For respondents who did NOT work with FA):** two months ago,

put an **X** on this line to show how well your family was doing at that time. [200]

Now, on this line, put an **X** to show how well your family is doing right now. [201]

FAMILY ID#: _____

HOW WELL MY FAMILY WAS AND IS DOING



Before moving on to the questionnaires, is there anything you would like to add or comment on, or are there any additional reactions to getting **(child's name)** started in mental health services you would like to give us? _____

* * * * * * * *

INTRODUCING THE QUESTIONNAIRES

We have finished the first part of this interview. Now I would like to ask you to fill out a few questionnaires. It should take about 20 to 30 minutes. Again, we have three options for you. You can read the questionnaires in English, or we have them in Spanish, or I could read them to you. Which would you prefer? **(Give a brief overview for each of the questionnaires. Point out the parts of the CBCL that are not completed. Emphasize that the questionnaires are double-sided. When s/he is done filling them out, say):** Did you have any questions about any of the items?

(Respond to any questions s/he may have. If help is needed to understand an item, do your best to rephrase the item without changing the meaning of the item or providing the respondent with any additional information. Review each questionnaire to make sure all of the items were answered and say): I just need to quickly glance through these to make sure everything is filled out.

CLOSING SUMMARY FOR FOLLOW-UP INTERVIEW

If the respondent cannot complete the questionnaires, give her/him the option of keeping them to finish and schedule a time to pick them up within 2-4 days. Explain that s/he will receive the $25 when the forms are completed and picked-up. Thank the respondent for her/his time and help.)

For those who complete all of the questionnaires, say): Thank you very much for participating in this interview. You have helped us a lot and we appreciate your time. Here is your $25 check. Please sign this receipt to show that you have received the $25 for this follow-up interview.

We hope to conduct another interview with you and other families in the future. It would probably happen sometime within a year. As we have done for the first two interviews, we would pay families for doing that interview. If it occurs, would you be willing to let us contact you again?

If NO): Again, thank you for your time. I have enjoyed talking with you.

If YES, read): Let's read over this form, which allows us to contact you for another interview, and to answer any questions you may have. Again, thank you for your time. I have enjoyed talking with you.

FAMILY CONNECTIONS PROJECT

FOLLOW-UP INTERVIEW -- COMPARISON

	Today's Date:	Interviewer:
	First Interview Date:	

[1-6] [7-12]

INTRODUCTION

As I mentioned on the phone, this is a follow-up interview to the interview you did about 3-4 months ago for the Family Connections Project. Before we begin, I would like to review the Consent form you signed before. As you recall, this form was the way for you to agree to be a part of this project and describes the confidential nature of the information you give us. I would like you to review it. You can review it in English or in Spanish, or I can read it to you. Which would you prefer? When you are finished, I will answer any questions you have. **(Hand the Informed Consent form to the respondent.)** Do you have any questions? **(Make sure you remind the respondent about the exceptions to confidentiality.)**

During this interview, I will be asking you questions about **(child's name)**, the mental health services he/she received, how satisfied you were with those services and any problems you may have experienced. I will also ask you about any changes in your family circumstances that have occurred since the first interview. This interview will last about 1 to 1-1/2 hours. Because your time is valuable, the Regional Research Institute will pay you $25 for this interview.

As in the first interview, I will be writing down your answers as you give them to me. At times it may seem strange that I am writing and not looking at you when you talk. This is not because I am not interested in what you have to say. I want to be sure I write exactly what you say. When I have finished asking you questions, I will give you some forms to fill-out. We can stop the interview at any time to take a break if you wish. You have the right to skip any of the questions I ask you. Please take your time answering the questions. We want you to give your most honest opinions.

Do you have any questions about the research or the interview before we begin?

I WOULD LIKE TO BEGIN BY ASKING YOU QUESTIONS ABOUT (child's name), YOU, AND YOUR HOUSEHOLD. THIS INFORMATION WILL HELP US UNDERSTAND HOW (child's name) CURRENT SITUATION AND FAMILY CIRCUMSTANCES MAY INFLUENCE HER/HIS MENTAL HEALTH SERVICES. THIS INFORMATION WILL BE USED FOR RESEARCH PURPOSES ONLY AND WILL NOT BE SHARED WITH ANY OTHER PERSON OR AGENCY.

Respondent's FIRST name: **Child's FIRST name:**

1. Is **(child's name)** currently living with you? ___ YES_1 **(Go to #2)** ___ NO_2 [13]
   (If NO, ask): Where is she/he living now? _____ [14]

2. Did **(child's name)** consistently live with you since the first interview?
   ___ YES_1 **(Go to #3)** ___ NO_2 [15]

   (If NO, ask): Where else has she/he lived? _____
   (If NO, ask): For how long? _____

3. Is **(child's name)** currently enrolled in school, including home school?

___ **YES_1** [16]

3a. **(If YES, ask):** What is her/his current grade in school? _____ [17-18]

3b. **(If YES, ask):** Does **(child's name)** have an IEP (Individualized Education Plan)? An IEP looks like this **(show example)**.
___ YES_1 ___ DON'T $KNOW_3$ **(after adequate probing; Go to #4)** [19]
___ NO_2 **(Go to #4)**
→ **(If has IEP, ask):** What is the disabling condition s/he has an IEP for?
_____ [20-25]
→ **(If has IEP, ask):** What services is s/he receiving because of the IEP?
_____ [26-31]
(Go to #4)

___**NO_2** 3c. **(If NO, ask):** Why is s/he not enrolled in school? **(primary reason)**
___ too $young_1$ ___ between $schools_4$
___ $dropped\ out_2$ ___ summer $vacation_5$ **(ask #3d and #3e)**
___ $expelled_3$ ___ $other_6$: _____ [32]

3d. **(If NO, ask):** What was the last grade s/he completed? _____ [33-34]
(If on SUMMER VACATION, Go to #3e; otherwise Go to #4)

3e. **(If on SUMMER VACATION, ask):** Did **(child's name)** have an IEP (Individualized Education Plan) at the end of the last school year? An IEP looks like this **(show example)**. ___ YES_1 ___ NO_2 **(Go to #4)** [35]
→ **(If had IEP, ask):** What is the disabling condition s/he had an IEP for?
_____ [36-41]
→ **(If had IEP, ask):** What services was s/he receiving because of the IEP?
_____ [42-47]

4. When the first interview was done, **(child's name)** had a medical card. Does she/he still have a medical Card?

___ YES$_1$ **(Go to #5)** ___ NO$_2$ [48]

4a. **(If NO, ask):** Why doesn't she/he have a medical card anymore?

_____ [49]

5. As you may recall from the first interview, we wanted to get a sense for the caregiving responsibility you have. To do that, we asked you to tell us the number of people living in your home and how many of those people you had to spend time taking care of. Since the first interview, have there been any changes in the number of people who are living in your home?

___ YES$_1$ **(Ask #5a and #5b)** ___ NO$_2$ **(Go To #6)** [50]

(If the respondent is not sure what s/he said the first time, ask #5a and #5b.)

5a. **(If YES, ask):** Please tell me just the AGES of all the people in your home other than you and **(child's name)**.

Person	Age	Care	Person	Age	Care
#1	____[51-52]	____[53]	#4	____[60-61]	____[62]
#2	____[54-55]	____[56]	#5	____[63-64]	____[65]
#3	____[57-58]	____[59]	#6	____[66-67]	____[68]

___ **N/A: Respondent and Child are the ONLY people in the home. (Go To #6)**

5b. **(If any teens [13 years & up] or adults are listed, ask):** Do any of the teenagers/adults who are living with you require extra care from you because they have a disability, for example, a physical handicap, a chronic illness, a developmental handicap, or a serious emotional handicap? **(Put a ✔ in the "Care" column by the people identified as dependent.)**

6. Do you have someone who shares daily parenting/caregiving responsibilities with you?

___ YES$_1$ ___ NO$_2$ **(Go To #7)** [69]

6a. **(If YES, ask):** What is their relationship to you? **(primary person)**

___ Spouse/Partner$_1$ ___ Multiple Relatives$_4$ ___ Friend(s)$_7$

___ Parent$_2$ ___ Sibling$_5$ ___ Babysitter$_8$

___ Other Relative$_3$ ___ Boy/Girlfriend$_6$ ___ Other$_9$: _____ [70]

7. Have you moved since the first interview? ___ Yes$_1$ ___ No$_2$ **(Go To #8)** [71]

7a. **(If MOVED, ask):** What city/town do you list as your address? _____ [72]

7b. **(If MOVED, ask):** Do you live within this city/town's limits?
___ YES$_1$ (Go to #7c) **___ NO$_2$** **___ DON'T KNOW$_3$** [73]
→ **(If NO or DON'T KNOW, ask):** How many miles from this city/town do you live?
_____Miles. [74-75]

7c. **(If MOVED, ask):** How many miles do you live from:
_____ (miles) the nearest Post Office [76-77]
_____ (miles) the nearest Public Library [78-79]
_____ (miles) the nearest hospital [80-81]
_____ (miles) your child's school [82-83]
_____ (miles) the mental health office
(child's name) is/was going to [84-85]

7d. **(If MOVED, ask):** Are there any times of the year when you cannot travel?
___ YES$_1$ ___ NO$_2$ **(Go to #8)** [86]
→ ***(If YES, ask):*** When, for how long, and why can't you travel?: _____
_____

8. Do you consider your family as living in an area that is RURAL or URBAN **(circle one)**? [87]
COMMENTS: _____
_____

NOW I WOULD LIKE TO ASK YOU ABOUT THE MENTAL HEALTH SERVICES **(CHILD'S NAME)** HAS RECEIVED SINCE THE FIRST INTERVIEW.

9. Has **(child's name)** received any mental health services since the first interview for this project?

___ YES$_1$ **(Go to #10)** [88]

___ NO$_2$ **(If NO, ask):** I am going to read you a list of things that can get in a parent's way of getting their child to mental health services. Please tell me if any of these kept you from getting **(child's name)** started in mental health services.

(Read each item; check all that apply; record anecdotal information.)

___ Transportation problems [89]
___ Child care problems [90]
___ Was too far to travel [91]
___ Time conflict [92]
___ Child refused to be in treatment [93]
___ Confused about next step [94]
___ Would have been disruptive to regular family routine [95]
___ Decided child did not need mental health services [96]
___ Didn't think mental health services would help [97]
___ Didn't feel comfortable being associated with mental health services [98]
___ Didn't think mental health services would meet child's and/or your ethnic/cultural needs [99]
___ Thought it would conflict with child's and/or your religious beliefs or spirituality [100]
___ Didn't think anyone would speak child's and/or your language (includes sign language) [101]
___ Other: _____ [102]
___ NONE APPLY

(Go To #23)

10. A child will usually receive a mental health evaluation before treatment/counseling begins. The evaluation is done to identify the child's difficulties and decide what services are needed. Did **(child's name)** receive a mental health evaluation?

___ **YES$_1$** [103]

(If YES, ask): Were you given the results of that evaluation? ___ YES$_1$ ___ NO$_2$ [104]

→ **(If results were given, ask):**

Were you shown a copy of the written report? ___ YES$_1$ ___ NO$_2$ [105]

Did the therapist verbally review the results with you? ___ YES$_1$ ___ NO$_2$ [106]

___ **NO$_2$ (Go to #12)**

___ **DON'T KNOW$_3$ (Go to #12)**

11. **(Hand the CHOICES card):** Looking at LIST A on the CHOICES card, generally how satisfied were you with the mental health evaluation for **(child's name)**? **(Circle their choice.)**

1	2	3	4	5
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied

[107]

COMMENTS: _____

_____

12. Were you given a name or diagnosis for **(child's name)** condition or disorder?

___ **YES$_1$** [108]

(If YES, ask): What is the name or diagnosis you were given? **(Check all that apply.)**

___ Don't know/Can't recall [109]
___ Adjustment Disorder [110]
___ Anxiety Disorder [111]
___ Attachment Disorder [112]
___ Attention Deficit Hyperactivity Disorder (ADHD) [113]
___ Autistic Disorder [114]
___ Avoidant Disorder [115]
___ Bipolar Disorder (Manic-Depression) [116]
___ Childhood Depression [117]
___ Conduct Disorder [118]
___ Developmental Disorder (Mental Retardation) [119]
___ Eating Disorder (Anorexia, Bulimia, or Obesity) [120]
___ Enuresis/Encopresis [121]
___ Learning Disability [122]
___ Obsessive Compulsive Disorder [123]
___ Oppositional Disorder [124]
___ Phobia [125]
___ Post Traumatic Stress Disorder (PTSD) [126]
___ Schizophrenia [127]
___ Substance Abuse/Dependence [128]
___ Tourette's Syndrome [129]
___ Other: _____ [130]

___ **NO$_2$**

3. Other than a mental health evaluation, what type(s) of mental health services has **(child's name)** received? **(check all that apply)**

___ Individual therapy [131] ___ Family therapy [133]
___ Group therapy [132] ___ Day treatment [134]
___ Other:_____ [135]

4. How often do the scheduled appointments occur?
___ 1/week$_1$ ___ 1/two weeks$_2$ ___ 1/month$_3$
___ Other$_4$: _____ [136]

14a. Looking at List B on the CHOICES card, generally how do you feel about how often the appointments occur? **(circle their choice)**

1	2	3
Not Often Enough	Just Right	Too Often

[137]

COMMENTS: _____

_____

_____

5. How many mental health appointments has **(child's name)** attended?
(Encourage respondent to make her/his best guess. When necessary, show calendar to help respondent recall first appointment and count forward.)

_____ Appointments Attended [138-139]
_____ N/A; Child in Day Treatment (i.e., not attending isolated appointments)

16. Were there any scheduled appointments that **(child's name)** and/or you had to miss?

___ **YES**$_1$ [140]

(If YES, ask): How many appointments were missed? _____ [141]
(Use the calendar, if helpful)

(If YES, ask): I am going to read you a list of things that can get in a parent's way of getting their child to mental health appointments. Please tell me if any of these were reasons why **(child's name)** was unable to attend some of her/his mental health appointments. **(Read each item; check all that apply; record anecdotal information.)**

___ Transportation problems [142]
___ Child care problems [143]
___ Was too far to travel [144]
___ Time conflict [145]
___ Child refused to attend treatment sessions [146]
___ Was disruptive to regular family routine [147]
___ Decided child did not need mental health services [148]
___ Didn't feel the mental health services were helping [149]
___ Didn't feel comfortable being associated with mental health services [150]
___ Didn't think mental health services were meeting child's and/or your ethnic/cultural needs [151]
___ Mental health services conflicted with child's and/or your religious beliefs or spirituality [152]
___ Mental health worker didn't speak child's and/or your language (includes sign language) [153]
___ Disagreed with diagnosis or treatment approach [154]
___ Didn't like therapist/counselor/social worker/program [155]
___ Other: _____ [156]
___ NONE APPLY **(Go to #17)**

___ **NO**$_2$

17. Were the services **(child's name)** received the type you expected she/he would get?
___ YES$_1$ **(Go To #18)** ___ NO$_2$ [157]

17a. **(If NO, ask):** How have they been different?_____

_____

_____

_____

_____

18. Is **(child's name)** still receiving mental health services?

___ **YES**$_1$ [158]

(If YES, ask): What type of services is she/he receiving now? **(check all that apply)**

___ Individual therapy [159] ___ Family therapy [161] ___ Other:_____ [163]

___ Group therapy [160] ___ Day treatment [162] **(Go To #19)**

___ **NO**$_2$ **(If NO, ask):** I am going to read you a list of things that can get in the way of getting a child to mental health services. Please tell me if any of these were reasons for **(child's name)** ENDING mental health services.

(Read each item; check all that apply; record anecdotal information.)

___ Therapist said treatment was completed [164]

___ Child doing better, we chose to end treatment [165]

___ Transportation problems [166]

___ Child care problems [167]

___ Was too far to travel [168]

___ Time conflict [169]

___ Child refused to be in treatment [170]

___ Was disruptive to regular family routine [171]

___ Didn't feel the mental health services were helping [172]

___ Didn't feel comfortable being associated with mental health services [173]

___ Didn't think mental health services were meeting child's and/or your ethnic/cultural needs [174]

___ Mental health services conflicted with child's and/or your religious beliefs or spirituality [175]

___ Mental health worker didn't speak child's and/or your language (includes sign language) [176]

___ Didn't like therapist/counselor/social worker/program [177]

___ Disagreed with diagnosis or treatment approach [178]

___ Other: _____ [179]

___ NONE APPLY

19. **(Hand the CHOICES card):** Looking at List A on this CHOICES card, generally, how satisfied have you been with the mental health services **(child's name)** received? **(Circle their choice.)**

1	2	3	4	5
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied

[180]

COMMENTS: _____

_____

20. Looking at LIST A, generally how satisfied are you with how you have been treated as a parent/caregiver during **(child's name)** mental health services? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[181]

COMMENTS: _____

_____

21. Looking at LIST A, generally how satisfied are you with the therapist(s) or counselor(s) who provided the mental health services for **(child's name)**? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[182]

COMMENTS: _____

_____

22. Looking at LIST A, generally how satisfied are you with the level of involvement you had in **(child's name)** mental health services? **(Circle their choice.)**

1	2	3	4	5	
Very Satisfied	Satisfied	Mixed Feelings	Dissatisfied	Very Dissatisfied	[183]

COMMENTS: _____

_____

23. Since the first interview for this project, have you participated in a parent support group?

___ **YES**$_1$ ___ **NO**$_2$ **(Go to #24)** [184]

23a. **(If YES, ask):** Looking at LIST C on the CHOICES card, generally how do you feel about having participated in the parent support group?

1	2	3	4	5	
All Good	Mostly Good, Some Bad	Half Good, Half Bad	Mostly Bad, Some Good	All Bad	[185]

COMMENTS: _____

_____

COMPARISON FAMILIES

THE GOAL OF THIS RESEARCH PROJECT IS TO LEARN WHAT PARENTS NEED TO MAKE IT EASIER WHEN THEY ARE JUST GETTING STARTED IN THE CHILDREN'S MENTAL HEALTH SYSTEM. I WILL ASK YOU SOME QUESTIONS ABOUT THINGS THAT WOULD HAVE BEEN HELPFUL FOR YOU. I'D LIKE YOU TO THINK BACK OVER THE PAST FEW MONTHS, SINCE (CHILD'S NAME) WAS REFERRED FOR MENTAL HEALTH SERVICES, AND USE YOUR IMAGINATION TO COME UP WITH ANYTHING THAT WOULD HAVE MADE THE PROCESS EASIER FOR YOU. THE ANSWERS YOU GIVE ME WILL BE COMBINED WITH THOSE OF OTHER PARENTS AND WILL BE PRESENTED TO THE PEOPLE WHO MANAGE CHILDREN'S MENTAL HEALTH. THE GOAL IS TO IMPROVE THE SYSTEM.

23. Thinking back to when **(child's name)** was referred for mental health servies, in general, what things could have made the process easier for you? **(Encourage the respondent to be as creative as possible, no matter how unrealistic their ideas may be.)**

24. **I WOULD LIKE TO ASK YOU ONE LAST QUESTION. THIS IS ABOUT HOW YOUR FAMILY IS DOING NOW COMPARED TO OVER THE LAST FEW MONTHS.**

(Show respondent graph): This is a graph that will show how well your family was doing at two times in the past and right now. By "how well your family was doing" I mean, in general, how well your family was communicating, dealing with disagreements, and solving problems. Looking at the graph, this line ranges from "Really Great" to "Not Great, But OK" to "Really Badly". We will be using that range to describe your family.

Let's start when you were first interviewed for this project on _____ **(See first page for date).** Thinking back to that time, put an **X** on this line to show how well your family was doing.
(If necessary, help the respondent decide where to put the X. Make sure you do NOT decide for them, but rather just help them understand and manage the task.) [186]

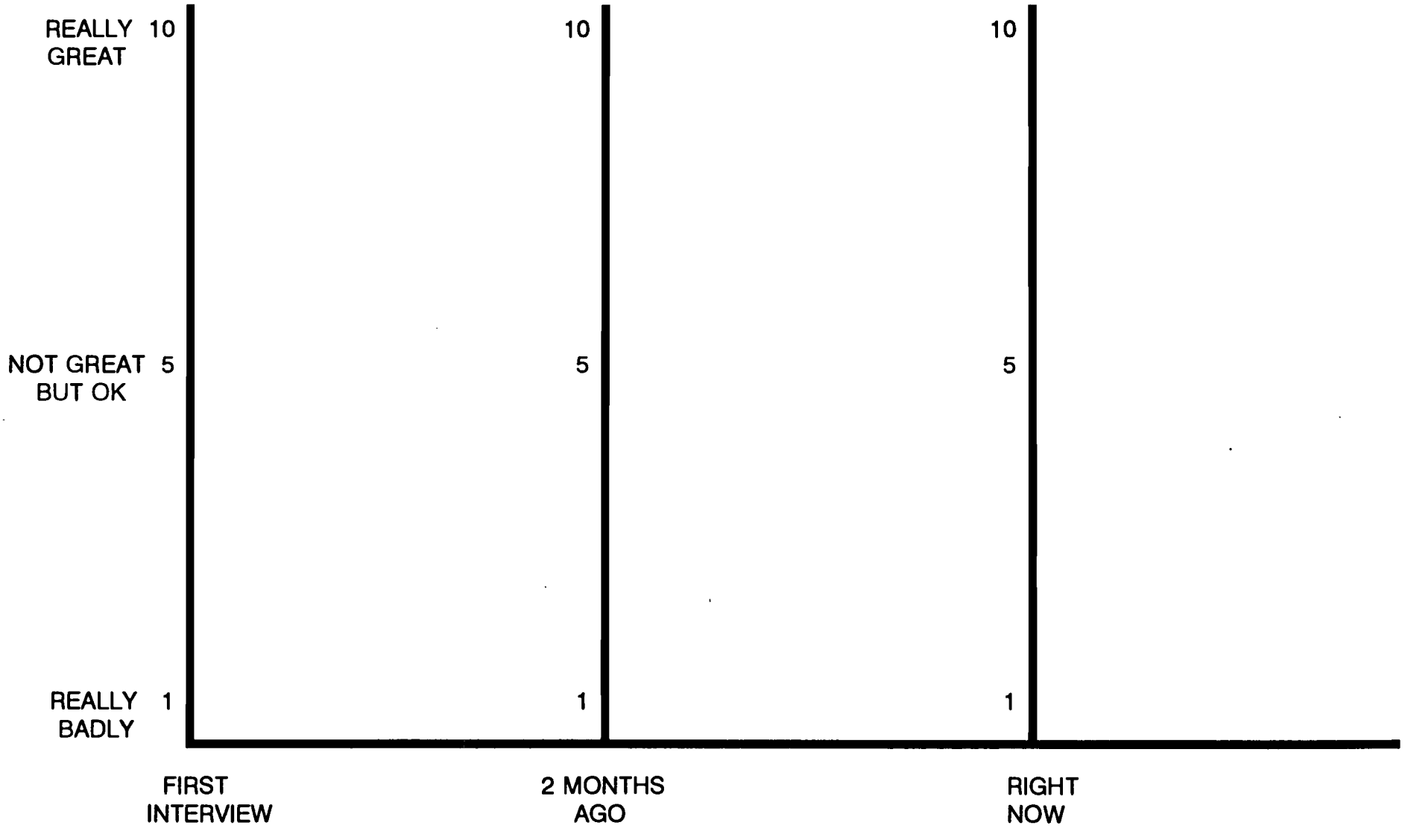
Now, thinking back to two months ago, which would be about _____, please put an **X** on this line to show how well your family was doing at that time. [187]

Now, on this line, put an **X** to show how well your family is doing right now. [188]

Before moving on to the questionnaires, is there anything you would like to add or comment on, or are there any additional reactions to getting **(child's name)** started in mental health services you would like to give us? _____

FAMILY ID#: _____

HOW WELL MY FAMILY WAS AND IS DOING



* * * * * * * *

INTRODUCING THE QUESTIONNAIRES

We have finished the first part of this interview. Now I would like to ask you to fill out a few questionnaires. It should take about 25 to 30 minutes. Again, we have three options for you. You can read the questionnaires in English, or we have them in Spanish, or I could read them to you. Which would you prefer? **(Give a brief overview for each of the questionnaires. Point out the parts of the CBCL that are not completed. Emphasize that the questionnaires are double-sided. When s/he is done filling them out, say):** Did you have any questions about any of the items?

(Respond to any questions s/he may have. If help is needed to understand an item, do your best to rephrase the item without changing the meaning of the item or providing the respondent with any additional information. Review each questionnaire to make sure all of the items were answered and say): I just need to quickly glance through these to make sure everything is filled out.

CLOSING SUMMARY FOR FOLLOW-UP INTERVIEW

(If the respondent cannot complete the questionnaires, give her/him the option of keeping them to finish and schedule a time to pick them up within 2-4 days. Explain that s/he will receive the $25 when the forms are completed and picked-up. Thank the respondent for her/his time and help.)

(For those who complete all of the questionnaires, say): Thank you very much for participating in this interview. You have helped us a lot and we appreciate your time. Here is your $25 check. Please sign this receipt to show that you have received the $25 for this follow-up interview.

We hope to conduct another interview with you and other families in the future. It would probably happen sometime within a year. As we have done for the first two interviews, we would pay families for doing that interview. If it occurs, would you be willing to let us contact you again?

(If NO): Again, thank you for your time. I have enjoyed talking with you.

(If YES, read): Let's read over this form, which allows us to contact you for another interview, and to answer any questions you may have. Again, thank you for your time. I have enjoyed talking with you.

APPENDIX H

Initial and Follow-Up Questionnaires:

CBCL[a]
F-COPES[a]
Family Empowerment Scale[a]
Family Barriers Scale[b]
(Intervention and Comparison Group Versions)

[a]Completed for both initial and follow-up assessments. The same version was used at both assessment points and for both groups.
[b]Completed only for the follow-up assessment.

CHILD BEHAVIOR CHECKLIST FOR AGES 4-18

For office use only
ID #

CHILD'S NAME

SEX ☐ Boy ☐ Girl

AGE

ETHNIC GROUP OR RACE

TODAY'S DATE
Mo. _____ Date _____ Yr. _____

CHILD'S BIRTHDATE
Mo. _____ Date _____ Yr. _____

GRADE IN SCHOOL _____

NOT ATTENDING SCHOOL ☐

Please fill out this form to reflect *your* view of the child's behavior even if other people might not agree. Feel free to write additional comments beside each item and in the spaces provided on page 2.

PARENTS' USUAL TYPE OF WORK, even if not working now. *(Please be specific—for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)*

FATHER'S TYPE OF WORK: _____

MOTHER'S TYPE OF WORK: _____

THIS FORM FILLED OUT BY:

☐ Mother (name): _____

☐ Father (name): _____

☐ Other—name & relationship to child: _____

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

a. _____

b. _____

c. _____

Compared to others of the same age, about how much time does he/she spend in each?

	Don't Know	Less Than Average	Average	More Than Average
a.	☐	☐	☐	☐
b.	☐	☐	☐	☐
c.	☐	☐	☐	☐

Compared to others of the same age, how well does he/she do each one?

	Don't Know	Below Average	Average	Above Average
a.	☐	☐	☐	☐
b.	☐	☐	☐	☐
c.	☐	☐	☐	☐

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, cars, singing, etc. (Do not include listening to radio or TV.)

☐ None

a. _____

b. _____

c. _____

Compared to others of the same age, about how much time does he/she spend in each?

	Don't Know	Less Than Average	Average	More Than Average
a.	☐	☐	☐	☐
b.	☐	☐	☐	☐
c.	☐	☐	☐	☐

Compared to others of the same age, how well does he/she do each one?

	Don't Know	Below Average	Average	Above Average
a.	☐	☐	☐	☐
b.	☐	☐	☐	☐
c.	☐	☐	☐	☐

III. Please list any organizations, clubs, teams, or groups your child belongs to.

☐ None

a. _____

b. _____

c. _____

Compared to others of the same age, how active is he/she in each?

	Don't Know	Less Active	Average	More Active
a.	☐	☐	☐	☐
b.	☐	☐	☐	☐
c.	☐	☐	☐	☐

IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.)

☐ None

a. _____

b. _____

c. _____

Compared to others of the same age, how well does he/she carry them out?

	Don't Know	Below Average	Average	Above Average
a.	☐	☐	☐	☐
b.	☐	☐	☐	☐
c.	☐	☐	☐	☐

1-91 Edition

V. 1. About how many close friends does your child have? (Do not include brothers & sisters) ☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

2. About how many times a week does your child do things with any friends outside of regular school hours? (Do not include brothers & sisters) ☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

VI. Compared to others of his/her age, how well does your child:

	Worse	About Average	Better	
a. Get along with his/her brothers & sisters?	☐	☐	☐	☐ Has no brothers or sisters
b. Get along with other kids?	☐	☐	☐	
c. Behave with his/her parents?	☐	☐	☐	
d. Play and work by himself/herself?	☐	☐	☐	

VII. 1. For ages 6 and older—performance in academic subjects. If child is not being taught, please give reason _____

	Failing	Below average	Average	Above average
a. Reading, English, or Language Arts	☐	☐	☐	☐
b. History or Social Studies	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Science	☐	☐	☐	☐
Other academic subjects—for example: computer courses, foreign language, business. Do *not* include gym, shop, driver's ed., etc. e. _____	☐	☐	☐	☐
f. _____	☐	☐	☐	☐
g. _____	☐	☐	☐	☐

2. Is your child in a special class or special school? ☐ No ☐ Yes—what kind of class or school?

3. Has your child repeated a grade? ☐ No ☐ Yes—grade and reason

4. Has your child had any academic or other problems in school? ☐ No ☐ Yes—please describe

When did these problems start?

Have these problems ended? ☐ No ☐ Yes—when?

Does your child have any illness, physical disability, or mental handicap? ☐ No ☐ Yes—please describe

What concerns you most about your child?

Please describe the best things about your child:

Below is a list of items that describe children and youth. For each item that describes your child now or **within the past 6 months**, please circle the **2** if the item is **very true or often true** of your child. Circle the **1** if the item is **somewhat or sometimes true** of your child. If the item is **not true** of your child, circle the **0**. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 1. Acts too young for his/her age
0 1 2 2. Allergy (describe): _____
_____
0 1 2 3. Argues a lot
0 1 2 4. Asthma
0 1 2 5. Behaves like opposite sex
0 1 2 6. Bowel movements outside toilet
0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate, can't pay attention for long
0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): _____
_____
0 1 2 10. Can't sit still, restless, or hyperactive
0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness
0 1 2 13. Confused or seems to be in a fog
0 1 2 14. Cries a lot
0 1 2 15. Cruel to animals
0 1 2 16. Cruelty, bullying, or meanness to others
0 1 2 17. Day-dreams or gets lost in his/her thoughts
0 1 2 18. Deliberately harms self or attempts suicide
0 1 2 19. Demands a lot of attention
0 1 2 20. Destroys his/her own things
0 1 2 21. Destroys things belonging to his/her family or others
0 1 2 22. Disobedient at home
0 1 2 23. Disobedient at school
0 1 2 24. Doesn't eat well
0 1 2 25. Doesn't get along with other kids
0 1 2 26. Doesn't seem to feel guilty after misbehaving
0 1 2 27. Easily jealous
0 1 2 28. Eats or drinks things that are not food — *don't* include sweets (describe): _____
_____
0 1 2 29. Fears certain animals, situations, or places, other than school (describe): _____
_____
0 1 2 30. Fears going to school
0 1 2 31. Fears he/she might think or do something bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trouble
0 1 2 40. Hears sounds or voices that aren't there (describe): _____
_____
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, highstrung, or tense
0 1 2 46. Nervous movements or twitching (describe): _____
_____
0 1 2 47. Nightmares
0 1 2 48. Not liked by other kids
0 1 2 49. Constipated, doesn't move bowels
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy
0 1 2 52. Feels too guilty
0 1 2 53. Overeating
0 1 2 54. Overtired
0 1 2 55. Overweight
56. Physical problems without known medical cause:
0 1 2 a. Aches or pains (*not* headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (describe): _____
_____
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches or cramps
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): _____
_____

Please see other side

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 57. Physically attacks people
0 1 2 58. Picks nose, skin, or other parts of body (describe): _____
_____
0 1 2 59. Plays with own sex parts in public
0 1 2 60. Plays with own sex parts too much
0 1 2 61. Poor school work
0 1 2 62. Poorly coordinated or clumsy
0 1 2 63. Prefers being with older kids
0 1 2 64. Prefers being with younger kids
0 1 2 65. Refuses to talk
0 1 2 66. Repeats certain acts over and over; compulsions (describe): _____
_____
0 1 2 67. Runs away from home
0 1 2 68. Screams a lot
0 1 2 69. Secretive, keeps things to self
0 1 2 70. Sees things that aren't there (describe):
_____
_____
0 1 2 71. Self-conscious or easily embarrassed
0 1 2 72. Sets fires
0 1 2 73. Sexual problems (describe): _____
_____
_____
0 1 2 74. Showing off or clowning
0 1 2 75. Shy or timid
0 1 2 76. Sleeps less than most kids
0 1 2 77. Sleeps more than most kids during day and/or night (describe): _____
_____
0 1 2 78. Smears or plays with bowel movements
0 1 2 79. Speech problem (describe): _____
_____
0 1 2 80. Stares blankly
0 1 2 81. Steals at home
0 1 2 82. Steals outside the home
0 1 2 83. Stores up things he/she doesn't need (describe): _____
_____
0 1 2 84. Strange behavior (describe): _____
_____
0 1 2 85. Strange ideas (describe): _____
_____
0 1 2 86. Stubborn, sullen, or irritable
0 1 2 87. Sudden changes in mood or feelings
0 1 2 88. Sulks a lot
0 1 2 89. Suspicious
0 1 2 90. Swearing or obscene language
0 1 2 91. Talks about killing self
0 1 2 92. Talks or walks in sleep (describe): _____
_____
0 1 2 93. Talks too much
0 1 2 94. Teases a lot
0 1 2 95. Temper tantrums or hot temper
0 1 2 96. Thinks about sex too much
0 1 2 97. Threatens people
0 1 2 98. Thumb-sucking
0 1 2 99. Too concerned with neatness or cleanliness
0 1 2 100. Trouble sleeping (describe): _____
_____
0 1 2 101. Truancy, skips school
0 1 2 102. Underactive, slow moving, or lacks energy
0 1 2 103. Unhappy, sad, or depressed
0 1 2 104. Unusually loud
0 1 2 105. Uses alcohol or drugs for nonmedical purposes (describe): _____
_____
0 1 2 106. Vandalism
0 1 2 107. Wets self during the day
0 1 2 108. Wets the bed
0 1 2 109. Whining
0 1 2 110. Wishes to be of opposite sex
0 1 2 111. Withdrawn, doesn't get involved with others
0 1 2 112. Worries
113. Please write in any problems your child ha that were not listed above:
0 1 2 _____
0 1 2 _____
0 1 2 _____

UNDERLINE ANY YOU ARE CONCERNED ABO

Family ID#:_____

F-COPES
FAMILY CRISIS ORIENTED PERSONAL SCALES

DIRECTIONS
First, read the list of "Response Choices" one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle the number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
1 Sharing our difficulties with relatives	1	2	3	4	5
2 Seeking encouragement and support from friends	1	2	3	4	5
3 Knowing we have the power to solve major problems	1	2	3	4	5
4 Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5
5 Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6 Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7 Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5
8 Receiving gifts and favors from neighbors (e.g. food, taking in mail, etc.)	1	2	3	4	5
9 Seeking information and advice from the family doctor	1	2	3	4	5
10 Asking neighbors for favors and assistance	1	2	3	4	5
11 Facing the problems "head-on" and trying to get a solution right away	1	2	3	4	5
12 Watching television	1	2	3	4	5
13 Showing that we are strong	1	2	3	4	5
14 Attending church services	1	2	3	4	5
15 Accepting stressful events as a fact of life	1	2	3	4	5
16 Sharing concerns with close friends	1	2	3	4	5
17 Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18 Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19 Accepting that difficulties occur unexpectedly	1	2	3	4	5
20 Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
21 Seeking professional counseling and help for family difficulties	1	2	3	4	5
22 Believing we can handle our own problems	1	2	3	4	5
23 Participating in church activities	1	2	3	4	5
24 Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25 Asking relatives how they feel about problems we face	1	2	3	4	5
26 Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27 Seeking advice from a minister	1	2	3	4	5
28 Believing if we wait long enough, the problem will go away	1	2	3	4	5
29 Sharing problems with neighbors	1	2	3	4	5
30 Having faith in God	1	2	3	4	5

FAMILY STRESS COPING AND HEALTH PROJECT
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

Family Health Program
FORM A
1981

Hamilton I. McCubbin **David H. Olson** **Andrea S. Larsen**

FAMILY EMPOWERMENT SCALE

Instructions: Below are a number of statements that describe how a parent or caregiver of a child with an emotional problem may feel about his or her situation. For each statement, please circle the response that best describes how the statement applies to you.

1.	I feel that I have a right to approve all services my child receives.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
2.	When problems arise with my child, I handle them pretty well.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
3.	I feel I can have a part in improving services for children in my community.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
4.	I feel confident in my ability to help my child grow and develop.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
5.	I know the steps to take when I am concerned my child is receiving poor services.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
6.	I make sure that professionals understand my opinions about what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
7.	I know what to do when problems arise with my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
8.	I get in touch with my legislators when important bills or issues concerning children are pending.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
9.	I feel my family life is under control.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
10.	I understand how the service system for children is organized.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
11.	I am able to make good decisions about what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
12.	I am able to work with agencies and professionals to decide what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
13.	I make sure I stay in regular contact with professionals who are providing services to my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
14.	I have ideas about the ideal service system for children.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
15.	I help other families get the services they need.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
16.	I am able to get information to help me better understand my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
	)elieve that other parents and I can have an fluence on services for children.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$

PLEASE CONTINUE →

18.	My opinion is just as important as professionals' opinions in deciding what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
19.	I tell professionals what I think about services being provided to my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
20.	I tell people in agencies and government how services for children can be improved.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
21.	I believe I can solve problems with my child when they happen.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
22.	I know how to get agency administrators or legislators to listen to me.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
23.	I know what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
24.	I know what the rights of parents and children are under the special education laws.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
25.	I feel that my knowledge and experience as a parent can be used to improve services for children and families.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
26.	When I need help with problems in my family, I am able to ask for help from others.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
27.	I make efforts to learn new ways to help my child grow and develop.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
28.	When necessary, I take the initiative in looking for services for my child and family.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
29.	When dealing with my child, I focus on the good things as well as the problems.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
30.	I have a good understanding of the service system that my child is involved in.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
31.	When faced with a problem involving my child, I decide what to do and then do it.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
32.	Professionals should ask me what services I want for my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
33.	I have a good understanding of my child's disorder.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
34.	I feel I am a good parent.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$

Research and Training Center on Family Support and Children's Mental Health.
Regional Research Institute for Human Services, Portland State University, PO Box 751, Portland, OR 97207-0751.

FAMILY ID#:_____

Family Connections Project

FAMILY BARRIERS SCALE

(Intervention)

STEP 1: **Listed below are some things that can get in a parent's way of getting their child to mental health services. These things can be problems that keep a child from getting started in mental health services, cause appointments to be missed, or result in ending services before they are done. For each area listed below, please check (✓) the box to show how much of a problem it was for you as you were getting your child to mental health services.**

	Not A Problem$_1$	Slight Problem$_2$	Moderate Problem$_3$	Major Problem$_4$	Comments*
1. Transportation to mental health services	☐	☐	☐	☐	_____
2. Child care for other children during mental health appointments	☐	☐	☐	☐	_____
3. Emotional support	☐	☐	☐	☐	_____
4. Information about mental health services	☐	☐	☐	☐	_____
5. Respite care (getting relief from child-caring responsibilities for a short time)	☐	☐	☐	☐	_____
6. Getting benefits (e.g., food stamps)	☐	☐	☐	☐	_____
7. Help with daily living tasks	☐	☐	☐	☐	_____
8. Contact with other parents who have children in mental health services	☐	☐	☐	☐	_____
9. Information about emotional/ behavioral disorders in children	☐	☐	☐	☐	_____
10. Information about recreational opportunities for children	☐	☐	☐	☐	_____
11. Not enough clothing	☐	☐	☐	☐	_____
12. Not enough food	☐	☐	☐	☐	_____
13. Paying for utilities	☐	☐	☐	☐	_____
14. _____	☐	☐	☐	☐	_____
15. _____	☐	☐	☐	☐	_____
16. _____	☐	☐	☐	☐	_____

STEP 2: **Please circle the number of each area that you worked on with your Family Associate.**

STEP 3: **Overall, how much did you need the Family Associate services? (circle the best choice)**

Not At All	Slightly	Moderately	Very Much
1	2	3	4

free to use the back of this sheet for additional comments, noting the item number by each comment.

FAMILY ID#:_____

Family Connections Project

FAMILY BARRIERS SCALE

(Comparison)

Listed below are some things that can get in a parent's way of getting their child to mental health services. These things can be problems that keep a child from getting started in mental health services, cause appointments to be missed, or result in ending services before they are done. For each area listed below, please check (✓) the box to show how much of a problem it was for you as you were getting your child to mental health services.

	Not A Problem$_1$	Slight Problem$_2$	Moderate Problem$_3$	Major Problem$_4$	Comments*
1. Transportation to mental health services	☐	☐	☐	☐	_____
2. Child care for other children during mental health appointments	☐	☐	☐	☐	_____
3. Emotional support	☐	☐	☐	☐	_____
4. Information about mental health services	☐	☐	☐	☐	_____
5. Respite care (getting relief from child-caring responsibilities for a short time)	☐	☐	☐	☐	_____
6. Getting benefits (e.g., food stamps)	☐	☐	☐	☐	_____
7. Help with daily living tasks	☐	☐	☐	☐	_____
8. Contact with other parents who have children in mental health services	☐	☐	☐	☐	_____
9. Information about emotional/ behavioral disorders in children	☐	☐	☐	☐	_____
10. Information about recreational opportunities for children	☐	☐	☐	☐	_____
11. Not enough clothing	☐	☐	☐	☐	_____
12. Not enough food	☐	☐	☐	☐	_____
13. Paying for utilities	☐	☐	☐	☐	_____
14. _____	☐	☐	☐	☐	_____
15. _____	☐	☐	☐	☐	_____
16. _____	☐	☐	☐	☐	_____

*Feel free to use the back of this sheet for additional comments, noting the item number by each comment.

APPENDIX I

Family Associate Data Collection Materials:

RIIFF
FA Activity Log
Nonparticipant Log

FAMILY CONNECTIONS PROJECT

FAMILY ASSOCIATE ACTIVITY LOG

Family ID#: ______________ County: ______________

DATE	PERSON CONTACTED/PHONE NUMBER (NO FAMILY/CLIENT NAMES)	CONTACT WHO?	CONTACT TYPE	TIME SPENT	SITE CODE	ACTIVITY CODES	COMMENTS/NOTES (DESCRIBE ANY EXPENDITURES)
		FAM PROF OTH	TELE IN-PERS OTH		OFF HOME OTH		
		FAM PROF OTH	TELE IN-PERS OTH		OFF HOME OTH		
		FAM PROF OTH	TELE IN-PERS OTH		OFF HOME OTH		
		FAM PROF OTH	TELE IN-PERS OTH		OFF HOME OTH		
		FAM PROF OTH	TELE IN-PERS OTH		OFF HOME OTH		
		FAM PROF OTH	TELE IN-PERS OTH		OFF HOME OTH		
		FAM PROF OTH	TELE IN-PERS OTH		OFF HOME OTH		
		FAM PROF OTH	TELE IN-PERS OTH		OFF HOME OTH		

CONTACT CODES:

WHO?:
FAM = Family Member
PROF = Professional
OTH = Other (Specify)

TYPE:
TELE = Telephone
IN-PERS = In-Person
OTH = Other (Specify)

SITE CODES:
OFF = Office
HOME = Home Visit
OTH = Other

ACTIVITY CODES:
SC = Scheduling
DC = Data Collection
$$ = Cash Support Fund
PI = Providing Information
FR = Finding Resources
PS = Providing Support

FAMILY ASSOCIATE ACTIVITY LOG
ACTIVITY CODES

SC = SCHEDULING
- ▸ Making initial contact with a family/telephone screening
- ▸ Scheduling appointments with a family
- ▸ Locating a family

DC = DATA COLLECTION
- ▸ Doing the initial research interview
- ▸ Picking up completed questionnaires
- ▸ Accumulating and mailing data to Debi

$$ = CASH SUPPORT FUND EXPENDITURE
- ▸ List all expenditures
- ▸ Specify the item and the amount spent in the Comments section

PI = PROVIDING INFORMATION
- ▸ Giving the family information about the mental health system, community resources, social services, etc.
- ▸ Teaching a family member how to most effectively utilize services they are receiving

FR = FINDING RESOURCES
- ▸ Locating community resources, social services, or mental health services for a family
- ▸ Modeling for or teaching a family member the skills of finding resources

PS = PROVIDING SUPPORT
- ▸ Giving a family member emotional support
- ▸ Listening to a family describe their current situation and their feelings associated with that situation
- ▸ Going with a family member while a child attends a mental health assessment or treatment session, or performs some other task about which the family member feels apprehensive or anxious

Family Connections Project
NON-PARTICIPANT LOG

Please record the reason(s) why a family you call chooses not to participate in the Family Connections Project. Record the child's age and gender if this information is available.

DATE CALLED	REASON(S) FOR NOT PARTICIPATING	CHILD'S AGE	CHILD'S GENDER
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F
			M F

1 to Debi when page is full.

FAMILY ID#:	DATE ENDED WITH FAMILY:	DATE FORM COMPLETED:

Family Connections Project

RATINGS OF IMPORTANT ISSUES FOR FAMILIES

STEP 1: Listed below are some issues that may be important to families when they are getting linked to mental health services for their children. For each issue listed, please indicate how important this issue was to the family with whom you have just completed working. Check the appropriate box for each issue.

	Not Important$_1$	Slightly Important$_2$	Moderately Important$_3$	Very Important$_4$	Comments*
___ 1. Transportation	☐	☐	☐	☐	_____
___ 2. Child care	☐	☐	☐	☐	_____
___ 3. Emotional support	☐	☐	☐	☐	_____
___ 4. Information about mental health services	☐	☐	☐	☐	_____
___ 5. Respite care	☐	☐	☐	☐	_____
___ 6. Getting benefits, e.g., food stamps	☐	☐	☐	☐	_____
___ 7. Help with daily living tasks	☐	☐	☐	☐	_____
___ 8. Contact with parent support group	☐	☐	☐	☐	_____
___ 9. Information about emotional/ behavioral disorders in children	☐	☐	☐	☐	_____
___ 10. Recreation	☐	☐	☐	☐	_____
___ 11. Clothing	☐	☐	☐	☐	_____
___ 12. Food	☐	☐	☐	☐	_____
___ 13. Utilities	☐	☐	☐	☐	_____
___ 14. _____	☐	☐	☐	☐	_____
___ 15. _____	☐	☐	☐	☐	_____
___ 16. _____	☐	☐	☐	☐	_____

STEP 2: Please identify the issues you worked on with this family by putting an X on the line in front of each relevant item.

STEP 3: In your opinion, how much did this family need the Family Associate services? (circle the best choice)

Not At All	Slightly	Moderately	Very Much
1	2	3	4

STEP 4: Report the travel time and distance from the County Mental Health Office to this family's home (one way):

Miles: _____ Minutes: _____

*Feel free to use the back of this sheet for additional comments, noting the item number by each comment.

APPENDIX J

Frequency Distributions for the:

Number of Appointments Attended (pp. 1-2)
Number of Appointments Missed (pp. 2-3)
Percent of Appointments Kept (pp. 4-5)
(Each VariablePresented Separately By
Total Sample, Intervention Group, and Comparison Group)

BER APPOINTMENTS ATTENDED: TOTAL SAMPLE

...TEND2 NUMBER OF APPOINTMENTS ATTENDED

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
	1	28	14.3	14.3	14.3
	2	11	5.6	5.6	19.9
	3	8	4.1	4.1	24.0
	4	10	5.1	5.1	29.1
	5	9	4.6	4.6	33.7
	6	21	10.7	10.7	44.4
	7	8	4.1	4.1	48.5
	8	18	9.2	9.2	57.7
	9	2	1.0	1.0	58.7
	10	20	10.2	10.2	68.9
	11	1	.5	.5	69.4
	12	21	10.7	10.7	80.1
	13	5	2.6	2.6	82.7
	14	4	2.0	2.0	84.7
	15	4	2.0	2.0	86.7
	16	9	4.6	4.6	91.3
	17	2	1.0	1.0	92.3
	18	3	1.5	1.5	93.9
	19	1	.5	.5	94.4
	20	6	3.1	3.1	97.4
	24	1	.5	.5	98.0
	25	1	.5	.5	98.5
	30	1	.5	.5	99.0
	32	1	.5	.5	99.5
	46	1	.5	.5	100.0
	Total	196	100.0	100.0	

Mean 8.546

Valid cases 196 Missing cases 0

NUMBER APPOINTMENTS ATTENDED: INTERVENTION GROUP

NATTEND2 NUMBER OF APPOINTMENTS ATTENDED

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
	1	10	11.6	11.6	11.6
	2	6	7.0	7.0	18.6
	3	1	1.2	1.2	19.8
	4	3	3.5	3.5	23.3
	5	6	7.0	7.0	30.2
	6	11	12.8	12.8	43.0
	7	3	3.5	3.5	46.5
	8	9	10.5	10.5	57.0
	10	8	9.3	9.3	66.3
	11	1	1.2	1.2	67.4
	12	9	10.5	10.5	77.9
	13	4	4.7	4.7	82.6
	14	2	2.3	2.3	84.9
	15	1	1.2	1.2	86.0
	16	4	4.7	4.7	90.7
	17	1	1.2	1.2	91.9
	18	1	1.2	1.2	93.0
	19	1	1.2	1.2	94.2
	20	2	2.3	2.3	96.5
	25	1	1.2	1.2	97.7
	30	1	1.2	1.2	98.8
	32	1	1.2	1.2	100.0
	Total	86	100.0	100.0	

Mean 8.895

Valid cases 86 Missing cases 0

SPSS/PC+ 5/12/95

NUMBER APPOINTMENTS ATTENDED: COMPARISON GROUP

NATTEND2 NUMBER OF APPOINTMENTS ATTENDED

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
	1	18	16.4	16.4	16.4
	2	5	4.5	4.5	20.9
	3	7	6.4	6.4	27.3
	4	7	6.4	6.4	33.6
	5	3	2.7	2.7	36.4
	6	10	9.1	9.1	45.5
	7	5	4.5	4.5	50.0
	8	9	8.2	8.2	58.2
	9	2	1.8	1.8	60.0
	10	12	10.9	10.9	70.9
	12	12	10.9	10.9	81.8
	13	1	.9	.9	82.7
	14	2	1.8	1.8	84.5
	15	3	2.7	2.7	87.3
	16	5	4.5	4.5	91.8
	17	1	.9	.9	92.7
	18	2	1.8	1.8	94.5
	20	4	3.6	3.6	98.2
	24	1	.9	.9	99.1
	46	1	.9	.9	100.0
	Total	110	100.0	100.0	

Mean 8.273

Valid cases 110 Missing cases 0

SPSS/PC+ 5/12/95

NUMBER APPOINTMENTS MISSED: TOTAL SAMPLE

NMISS2 NUMBER OF MISSED APPOINTMENTS

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
	0	71	36.2	36.2	36.2
	1	54	27.6	27.6	63.8
	2	27	13.8	13.8	77.6
	3	22	11.2	11.2	88.8
	4	9	4.6	4.6	93.4
	5	7	3.6	3.6	96.9
	6	2	1.0	1.0	98.0
	7	2	1.0	1.0	99.0
	9	2	1.0	1.0	100.0
	Total	196	100.0	100.0	

Mean 1.474

Valid cases 196 Missing cases 0

BER APPOINTMENTS MISSED: INTERVENTION GROUP

NMISS2 NUMBER OF MISSED APPOINTMENTS

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
	0	28	32.6	32.6	32.6
	1	21	24.4	24.4	57.0
	2	13	15.1	15.1	72.1
	3	13	15.1	15.1	87.2
	4	3	3.5	3.5	90.7
	5	6	7.0	7.0	97.7
	6	1	1.2	1.2	98.8
	9	1	1.2	1.2	100.0
	Total	86	100.0	100.0	

Mean 1.663

Valid cases 86 Missing cases 0

NUMBER APPOINTMENTS MISSED: COMPARISON GROUP

NMISS2 NUMBER OF MISSED APPOINTMENTS

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
	0	43	39.1	39.1	39.1
	1	33	30.0	30.0	69.1
	2	14	12.7	12.7	81.8
	3	9	8.2	8.2	90.0
	4	6	5.5	5.5	95.5
	5	1	.9	.9	96.4
	6	1	.9	.9	97.3
	7	2	1.8	1.8	99.1
	9	1	.9	.9	100.0
	Total	110	100.0	100.0	

Mean 1.327

Valid cases 110 Missing cases 0

SPSS/PC+ 5/12/95

PERCENT APPOINTMENTS KEPT: BOTH GROUPS

PERCKEPT

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
	33.33	2	1.0	1.0	1.0
	36.36	1	.5	.5	1.5
	40.00	2	1.0	1.0	2.6
	42.86	1	.5	.5	3.1
	44.44	1	.5	.5	3.6
	50.00	10	5.1	5.1	8.7
	54.55	2	1.0	1.0	9.7
	57.14	2	1.0	1.0	10.7
	58.82	1	.5	.5	11.2
	60.00	4	2.0	2.0	13.3
	62.50	4	2.0	2.0	15.3
	64.00	1	.5	.5	15.8
	66.67	10	5.1	5.1	20.9
	71.43	3	1.5	1.5	22.4
	72.73	2	1.0	1.0	23.5
	75.00	4	2.0	2.0	25.5
	76.92	4	2.0	2.0	27.6
	77.78	4	2.0	2.0	29.6
	78.95	2	1.0	1.0	30.6
	80.00	13	6.6	6.6	37.2
	81.82	1	.5	.5	37.8
	83.33	5	2.6	2.6	40.3
	84.21	1	.5	.5	40.8
	85.71	8	4.1	4.1	44.9
	86.67	1	.5	.5	45.4
	86.96	1	.5	.5	45.9
	87.50	4	2.0	2.0	48.0
	88.89	6	3.1	3.1	51.0
	90.00	1	.5	.5	51.5
	90.91	7	3.6	3.6	55.1
	91.67	1	.5	.5	55.6
	92.31	9	4.6	4.6	60.2
	92.86	1	.5	.5	60.7
	93.75	1	.5	.5	61.2
	94.74	2	1.0	1.0	62.2
	96.15	1	.5	.5	62.8
	96.97	1	.5	.5	63.3
	97.87	1	.5	.5	63.8
	100.00	71	36.2	36.2	100.0
	Total	196	100.0	100.0	

Mean 84.137

Valid cases 196 Missing cases 0

227

SPSS/PC+ 5/12/95

PERCENT APPOINTMENTS KEPT: INTERVENTION GROUP

PERCKEPT

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
	33.33	2	2.3	2.3	2.3
	44.44	1	1.2	1.2	3.5
	50.00	3	3.5	3.5	7.0
	54.55	2	2.3	2.3	9.3
	57.14	2	2.3	2.3	11.6
	60.00	1	1.2	1.2	12.8
	62.50	3	3.5	3.5	16.3
	64.00	1	1.2	1.2	17.4
	66.67	9	10.5	10.5	27.9
	71.43	1	1.2	1.2	29.1
	72.73	1	1.2	1.2	30.2
	75.00	2	2.3	2.3	32.6
	76.92	2	2.3	2.3	34.9
	77.78	2	2.3	2.3	37.2
	80.00	6	7.0	7.0	44.2
	85.71	4	4.7	4.7	48.8
	86.67	1	1.2	1.2	50.0
	87.50	1	1.2	1.2	51.2
	88.89	1	1.2	1.2	52.3
	90.91	4	4.7	4.7	57.0
	91.67	1	1.2	1.2	58.1
	92.31	3	3.5	3.5	61.6
	92.86	1	1.2	1.2	62.8
	93.75	1	1.2	1.2	64.0
	94.74	1	1.2	1.2	65.1
	96.15	1	1.2	1.2	66.3
	96.97	1	1.2	1.2	67.4
	100.00	28	32.6	32.6	100.0
	Total	86	100.0	100.0	

Mean 82.467

Valid cases 86 Missing cases 0

228

CENT APPOINTMENTS KEPT: COMPARISON GROUP

PERCKEPT

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
	36.36	1	.9	.9	.9
	40.00	2	1.8	1.8	2.7
	42.86	1	.9	.9	3.6
	50.00	7	6.4	6.4	10.0
	58.82	1	.9	.9	10.9
	60.00	3	2.7	2.7	13.6
	62.50	1	.9	.9	14.5
	66.67	1	.9	.9	15.5
	71.43	2	1.8	1.8	17.3
	72.73	1	.9	.9	18.2
	75.00	2	1.8	1.8	20.0
	76.92	2	1.8	1.8	21.8
	77.78	2	1.8	1.8	23.6
	78.95	2	1.8	1.8	25.5
	80.00	7	6.4	6.4	31.8
	81.82	1	.9	.9	32.7
	83.33	5	4.5	4.5	37.3
	84.21	1	.9	.9	38.2
	85.71	4	3.6	3.6	41.8
	86.96	1	.9	.9	42.7
	87.50	3	2.7	2.7	45.5
	88.89	5	4.5	4.5	50.0
	90.00	1	.9	.9	50.9
	90.91	3	2.7	2.7	53.6
	92.31	6	5.5	5.5	59.1
	94.74	1	.9	.9	60.0
	97.87	1	.9	.9	60.9
	100.00	43	39.1	39.1	100.0
	Total	110	100.0	100.0	

Mean 85.443

Valid cases 110 Missing cases 0

229

230

APPENDIX K

Barriers to Mental Health Service Initiation, Attendance, and Continuance Identified By Intervention and Comparison Families (Expansions of Table 6 of This Report)

Barriers to *Initiating* Mental Health Services

Group	Barrier (rank ordered by group)	n	%
Intervention (n = 7)	Child Care Problems	4	57
	Time Conflict	3	43
	Transportation Problems	2	29
	Child Refused Treatment	2	29
	Did Not Think MHS Would Help	2	29
	Confused About Next Step	2	29
	Child Did Not Need MHS	2	29
	Would Not Meet Cultural Needs	2	29
	Family Illness/Problems	2	29
	Too Far To Travel	1	14
	Discomfort Being Associated with MHS	1	14
	Conflict With Religious Beliefs	1	14
	Problems Connecting with MHS	1	14
Comparison (n = 28)	Time Conflict	12	43
	Confused About Next Step	12	43
	Child Did Not Need MHS	9	32
	Child Care Problems	4	29
	Transportation Problems	6	21
	Child Refused Treatment	6	21
	Did Not Think MHS Would Help	5	18
	Too Far To Travel	5	18
	Discomfort Being Associated with MHS	5	18
	Problems Connecting with MHS	5	18
	Would Not Meet Cultural Needs	2	7
	Forgot Appointment	2	7
	Coult Not Afford	2	7
	Family Illness/Problems	2	7
	Conflict With Religious Beliefs	1	4
	Would Not Speak Language	1	4
	Other	3	11

Barriers to *Attending* Mental Health Appointments

Group	Barrier (rank ordered by group)	n	%
Intervention (n = 59)	Time Conflict	28	48
	Transportation Problems	24	41
	Child Refused Treatment	12	20
	Family Illness	11	19
	Child Care Problems	9	15
	Too Far To Travel	7	12
	Forgot Appointment	7	12
	Disrupted Regular Family Routine	6	10
	Disagreed with Diagnosis/Treatment	5	9
	Family Problems	4	7
	Did Not Think MHS Were Helping	3	5
	Discomfort Being Associated with MHS	3	5
	Disliked Therapist/Program	3	5
	Problems Connecting with MHS	3	5
	Were Not Meeting Cultural Needs	2	3
	Child Did Not Need MHS	1	2
	Conflict With Religious Beliefs	1	2
	Other	1	2
Comparison (n = 70)	Time Conflict	31	44
	Family Illness	20	29
	Transportation Problems	19	27
	Forgot Appointment	10	14
	Child Care Problems	7	10
	Too Far To Travel	7	10
	Family Problems	5	7
	Problems Connecting with MHS	5	7
	Child Refused Treatment	4	6
	Disrupted Regular Family Routine	3	4
	Child Did Not Need MHS	3	4
	Did Not Think MHS Were Helping	2	3
	Discomfort Being Associated with MHS	2	3
	Disliked Therapist/Program	2	3
	Disagreed with Diagnosis/Treatment	1	1
	Would Not Meet Cultural Needs	1	1
	Other	4	6

U.S. Department of Education
Office of Educational Research and Improvement (OERI)
National Library of Education (NLE)
Educational Resources Information Center (ERIC)

REPRODUCTION RELEASE

(Specific Document)

I. DOCUMENT IDENTIFICATION:

Title: Family connections research demonstration project: Final report.

Author(s): Koroloff, N.M., Elliot, D.J., Koren, P.E., & Friesen, B.J.

Corporate Source: Regional Research Institute for Human Services ~~Portland State University~~

Publication Date: 1996

II. REPRODUCTION RELEASE:

In order to disseminate as widely as possible timely and significant materials of interest to the educational community, documents announced in the monthly abstract journal of the ERIC system, *Resources in Education* (RIE), are usually made available to users in microfiche, reproduced paper copy, and electronic media, and sold through the ERIC Document Reproduction Service (EDRS). Credit is given to the source of each document, and, if reproduction release is granted, one of the following notices is affixed to the document.

If permission is granted to reproduce and disseminate the identified document, please CHECK ONE of the following three options and sign at the bottom of the page.

The sample sticker shown below will be affixed to all Level 1 documents

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL HAS BEEN GRANTED BY

Sample

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

1

Level 1

☒

Check here for Level 1 release, permitting reproduction and dissemination in microfiche or other ERIC archival media (e.g., electronic) and paper copy.

The sample sticker shown below will be affixed to all Level 2A documents

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL IN MICROFICHE, AND IN ELECTRONIC MEDIA FOR ERIC COLLECTION SUBSCRIBERS ONLY, HAS BEEN GRANTED BY

Sample

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

2A

Level 2A

☐

Check here for Level 2A release, permitting reproduction and dissemination in microfiche and in electronic media for ERIC archival collection subscribers only

The sample sticker shown below will be affixed to all Level 2B documents

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL IN MICROFICHE ONLY HAS BEEN GRANTED BY

Sample

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

2B

Level 2B

☐

Check here for Level 2B release, permitting reproduction and dissemination in microfiche only

Documents will be processed as indicated provided reproduction quality permits.
If permission to reproduce is granted, but no box is checked, documents will be processed at Level 1.

I hereby grant to the Educational Resources Information Center (ERIC) nonexclusive permission to reproduce and disseminate this document as indicated above. Reproduction from the ERIC microfiche or electronic media by persons other than ERIC employees and its system contractors requires permission from the copyright holder. Exception is made for non-profit reproduction by libraries and other service agencies to satisfy information needs of educators in response to discrete inquiries.

Sign here, → please

Signature: Nancy Koroloff	Printed Name/Position/Title: Nancy M. Koroloff
Organization/Address: Regional Research Institute for Human Services	Telephone: 503-725-4157 FAX: 503-725-4180
	E-Mail Address: Date:

(over)