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Barriers to the Use of Preventive Health Care Services for Children

SYNOPSIS

THIS ARTICLE DESCRIBES findings from interviews of parents targeted for outreach efforts that encouraged them to use Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program. Begun in the 1970s, the EPSDT Program held out the promise of ensuring that needy children would receive comprehensive preventive health care. With only one-third of eligible children in the United States receiving EPSDT checkups, the program has yet to fulfill its promise. This study sought to understand parents' perceptions of barriers to using EPSDT by interviewing (a) 110 parents who did not schedule EPSDT checkups for their children after being exposed to outreach efforts and (b) 30 parents who did.

Although the EPSDT Program is designed to provide health care at no charge and to provide assistance with appointment scheduling and transportation, these low-income parents identified significant barriers to care. Reasons for not using EPSDT services included (a) competing family or personal issues and priorities; (b) perceived or actual barriers in the health care system; and (c) issues related directly to problems with the outreach efforts. Parents who successfully negotiated these barriers and received EPSDT services encountered additional barriers, for example, scheduling and transportation difficulties, long waiting room times, or care that they perceived to be either unresponsive to their medical needs or interpersonally disrespectful. The implications for future outreach efforts and improving access to preventive health care services are discussed.

In 1967, in conjunction with the Federal "War on Poverty," Congress created the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program. A component of Medicaid, EPSDT was intended to remove financial barriers to health care for needy children and ensure access to the comprehensive preventive services necessary for healthy growth and development. EPSDT services were first offered by the states in the 1970s and have been expanded substantially over the years, most significantly through provisions of the Omnibus Budget Reconciliation Acts of 1989¹ and 1990². Briefly, EPSDT services include complete health checkups at specified intervals, and more often if necessary; immunizations; and health education for parents regarding normal growth and development. The EPSDT Pro-

gram offers all medically necessary diagnostic and treatment services coverable by Medicaid, treatment for any problems detected during screening, as well as vision, dental, and hearing services³. All services are offered at no charge to Medicaid recipients from infancy to age 21. States are required to conduct outreach efforts to inform recipients about the program and to provide them with assistance in making appointments and arranging transportation for EPSDT-related care.

EPSDT clearly has the potential to make a positive impact on the health of the nation's children. Indeed, studies have shown that the program improves health and reduces health care costs⁴⁻⁹. However, a quarter century into implementation of the program, EPSDT services reach only one-third of the children eligible for care as noted in the Early and Periodic Screening, Diagnosis and Treatment transmittal notice, Region IV HCFA, 1991. Federal legislation^{1,2} requires the Secretary of the Department of Health and Human Services to set state goals for EPSDT participation. Federal goals for 1995 call for providing EPSDT checkups to 80% of all eligible children². The statutes do not provide explicit instructions for obtaining these goals though public health and social services agencies may expand their outreach efforts to encourage parents to use EPSDT services for their children.

Barriers to care are often seen in financial terms¹⁰, though nonfinancial barriers have also been studied¹¹⁻¹⁹. As part of an evaluation of EPSDT-related outreach, public health nurses interviewed parents in six rural North Carolina counties who did and did not use EPSDT services after being exposed to outreach efforts. The findings of this study document the reasons that parents gave for not using free preventive health services for their children and provide insights into the barriers surmounted by those who did use these services. These findings are particularly relevant in view of the current administration's priority to provide free preventive health services, for example, immunizations, to children whose families cannot afford to pay for care.

Methods

Setting and sample. Outreach efforts were targeted to parents of children in six rural, medically underserved counties in central North Carolina counties who were overdue for an EPSDT visit. We identified 2,214 heads of households that included at least one child eligible for Medicaid who, according to the state's Medicaid database, met the following criteria: children under one year old had never used EPSDT services; children ages one through 7 had not used EPSDT for more than a year; children 8 or older had not used EPSDT for more than two years.

Parents of Medicaid-eligible children were routinely informed about EPSDT services during periodic eligibility interviews. To test the effects of an enhanced outreach program we randomly assigned each of the 2,214 households in our outreach sample to one of the following approaches: (a)

pamphlet on program mailed with cover letter, (b) phone call with mailed pamphlet, or (c) home visits with pamphlet provided²⁰⁻²². At the same time that parent-focused outreach efforts were underway, private physicians in these counties also were being recruited by research staff in cooperation with county health departments to do EPSDT checkups²³⁻²⁴.

In the six counties, a disproportionate number of people live below the poverty level, many in housing units that lack indoor plumbing or are otherwise substandard²⁵. The majority of children eligible for Medicaid in these counties live in single-parent households headed by African American women²⁴. When our outreach efforts began in 1990, 14% to 36% of eligible children in these counties used EPSDT services²⁶.

This study reports the results of interviews with 30 heads of households whose children used EPSDT services and 110 who did not use EPSDT services following the outreach effort. In most cases the head of household, as designated on the Medicaid record, was the mother; in some cases it was the grandmother or father of the children. (In this article, for ease of reading, heads of households are referred to as "parents.")

Sampling procedure: nonusers. We selected a random sample of 226 parents from those who had not yet obtained EPSDT checkups for their children four to six months after being targeted for outreach. Public health nurses attempted to contact them by phone or home visit; 110 (49%) were successfully contacted. On being informed of the purposes and voluntary and confidential nature of the interview, all 110 agreed to be interviewed.

Sampling procedure: "new" users. The "new" users were 30 parents from the outreach sample whom the nurses interviewed by phone or home visit as part of a separate pilot study of the health outcomes of children. The 30 included all parents successfully contacted (79%) of a census of 38 who obtained checkups for their children during the first six months following the enhanced outreach efforts. The 30 parents contacted were informed of the purposes, confidentiality, and voluntary nature of the interview and, as part of the pilot study, also received payment of \$10 for their time; all agreed to be interviewed.

Data collection and analysis procedures. Public health nurses conducted the interviews by phone or, for parents without a phone, face-to-face in the home. The guide for interviews with nonusers included open-ended questions on (a) reasons for not using EPSDT and (b) suggestions for making it easier for parents to use EPSDT. The guide for interviews with "new" users included questions on (a) reasons for and experiences in using EPSDT or other preventive health care services and (b) suggestions for making it easier to use EPSDT.

Both interview guides were tested for validity. Content

validity was established through reviews by a panel of experts knowledge and experience in pediatrics, public health, nursing, health behavior, medical sociology, statistics, research design, and the EPSDT Program.

The interview guides were also tested for reliability. The nurses engaged in extensive training in which they used the guide for interviews with nonusers in mock interviews. The percent agreement between each nurse's coding of the mock subject's responses and a standardized script was calculated, providing an estimate of inter-rater reliability. All achieved reliability ratings of at least 90%.

To test the protocol for interviews with "new" users, one nurse interviewed each of five parents twice, one week apart; test-retest reliability was 78% \pm *sd* 3% agreement. Items that did not agree from test to retest differed quantitatively, not qualitatively. That is, with a time interval to think about responses, parents provided more responses to open-ended questions on the second interview than on the first.

Given the open-ended nature of the questions, the nurses took extensive notes during the interviews. We used content analysis to categorize responses to questions, such as "reasons why family didn't use EPSDT." We merged these responses with demographic information located in the State Medicaid databases. All analyses were descriptive, consistent with the nature of the interview data.

Results

Demographic characteristics. The demographic characteristics of the nonusers and "new" users were consistent with the characteristics of the target population from which the samples were drawn. With a few exceptions, the characteristics of the nonusers and "new" users were similar, as were the characteristics of those interviewed and those who could not be reached for interviews. (See Table 1). In comparison with

the target population and with the families that did not use EPSDT, families who did use EPSDT were more likely to have children under six years of age. New users also were more likely to have used EPSDT at some time in the past. Roughly 15 percent of those contacted and not contacted in both samples lost Medicaid eligibility within four months after outreach.

Nonusers' reasons for not using EPSDT services. Each of the 110 parents who did not use EPSDT services following outreach gave at least one reason for not doing so (Table 2); 13 gave two reasons and one gave three, suggesting an interplay of factors.... The most frequently cited reasons for nonuse, reported by 60 (55%) of the 110 parents, were family and personal issues that competed with the need for preventive health care. Nonhealth-related family or personal issues were reported by 35 parents (32%). Competing health concerns were cited by 27 (25%), two of whom also cited other family or personal issues.

Parents reported experiencing difficulties in arranging care for other children or family members, taking time off from work, managing personal problems, or handling family crises (for example, domestic disputes, severe illnesses, deaths). One mother described her own dire personal circumstances, severe health problems, and extreme poverty-level living conditions. Another, currently pregnant, talked about how difficult it was for her to get to the doctor herself. In addition, six respondents disclaimed responsibility for arranging care for their children, including fathers who said their wives were responsible and grandmothers who said their daughters (teenage mothers) were responsible.

Some parents stated or implied that they did not understand that all children need routine checkups. Fifteen stated that they did not believe children needed checkups unless the children were ill. Six said their children were ill so often

Table 1. Selected characteristics of families who did and did not use EPSDT following outreach effort

Characteristic	Did not use EPSDT (N = 226)				Used EPSDT (N = 38)		
	Interviewed (n=110)		Not reached for interview (n=116)		Interviewed (n=30)		Not reached for interview (n=8)
	Number	Percent	Number	Percent	Number	Percent	Number
Minority ethnicity.....	69	63	78	67	21	70	6
Phone in home.....	66	60	65	56	17	57	5
2 or more children.....	54	49	65	56	15	50	3
1 or more children under 6 years.....	37	34	50	43	14	47	6
Youngest child under 3 years.....	24	22	32	28	12	40	6
On AFDC.....	82	75	89	77	19	63	7
Agreed to enroll child in EPSDT services.....	83	75	97	84	24	80	8
Used EPSDT services in past 2 years for any child.....	20	18	18	16	12	40	5
Lost Medicaid eligibility ¹	17	15	18	16	5	17	4
Any Family member obtained non-EPSDT outpatient care ¹ ?.....	78	71	92	79	22	73	4
Any Family member hospitalized ¹ ?.....	7	6	4	3	3	10	1

¹< 4 months after outreach.

that it was difficult to schedule a well-child checkup. Five parents reported receiving some type of preventive medical care. Three of these thought that they had used the EPSDT Program, but a review of their Medicaid claims indicated that their children had received other kinds of medical care, not well-child checkups. One parent reported that a child had received immunizations, while another reported that a sports-related school physical was done; neither of these substitute for EPSDT checkups. A few parents said they did not use EPSDT because their children were under treatment for chronic illnesses (for example, asthma) or recent acute illnesses.

Perceived or actual barriers in the health care system were cited by 26 parents (24%) who tried to use the system but were unsuccessful in doing so (Table 2). These parents said they had problems in scheduling appointments because of inconvenient clinic hours or long delays in obtaining appointments. One mother described how she took her child for a scheduled checkup only to have the physician leave for an emergency without completing the checkup. Other parents cited difficulties related to the availability of health care providers; they disliked care at the public health clinic and could find no private provider nearby, or their own physician did not participate in the EPSDT Program and they did not want to change providers. Six parents said their children became ineligible for Medicaid before they could make an appointment for an EPSDT checkup. Indeed, for the children in 17 families (15%), Medicaid eligibility was disrupted during the four-month period following the outreach effort. Four parents, two of whom also cited other reasons for not using the EPSDT Program, indicated that transportation was a problem.

Thirty-five parents (32%) gave reasons for nonuse which suggested that the specific type of outreach method used (mailed pamphlet, phone call, or home visit) had failed either to reach the intended recipient or to convey the needed information (Table 2). Of these parents, 17 did not recall having received any type of outreach. (One of the 17 had been reached by phone, and 16 were among those who received outreach materials by mail.) Four parents recalled having received a pamphlet but either ignored it or could not read the outreach materials, which were written at the fourth- to sixth-grade reading level. Fourteen parents recalled having received a mailing, a phone call, or home visit but did not understand or did not remember the information presented about the EPSDT Program. Four of these 35 parents gave additional reasons for not using the program. Two parents—one of whom also reported a chronically ill child—were among those who disclaimed responsibility for the children's health care; one thought the child had had a checkup; one said she had not "gotten around to it"; and one said she did not know why she had not taken the child for an EPSDT checkup.

Nonusers' suggestions for making the EPSDT Program easier to use. Virtually all of the parents who did not sched-

ule checkups following the outreach effort had at least one suggestion for making preventive health care services easier to use. Their suggestions centered around two major areas: (a) conducting parent-focused outreach to inform people about EPSDT and motivate them to use the program and (b) making changes in the health care system. Many parents suggested using mailed pamphlets, phone calls, and home

Table 2. Reasons cited by 110 nonusers for continuing nonuse of EPSDT services.

Category/Reason	Number of parents ¹	Percent of sample ¹	95% Confidence Interval ²
Competing family or personal priorities or needs			
.....	60	55	47-67
Nonhealth-related issues			
Nonspecific reason ³	13	12	6-19
Conflict with specific family events (non-crisis).....	10	9	4-16
Family crisis.....	6	5	2-11
Someone else's responsibility	5	5	2-11
Health related issues	27	25	18-30
No perceived need for well-child checkup.....	15	14	8-21
Child had acute illness.....	6	5	2-11
Child had recent medical care.....	5	5	1-9
Child has chronic illness	3	3	1-7
Health care system barriers			
.....	26	24	17-34
Scheduling difficulties	9	8	4-15
Limited availability of providers	8	7	3-14
Loss of Medicaid eligibility	6	5	2-11
Transportation difficulties.....	4	4	1-9
Not adequately informed by outreach⁴			
.....	35	32	23-41
Did not remember receiving information ⁵	17	15	9-24
Remembered but did not understand information	14	13	7-20
Thought mailing was junk mail ⁶	2	2	1-6
Unable to read ⁶	2	2	1-6

¹Each of 110 parents gave at least one response; 14 gave multiple responses. Percentages are based on number of parents giving a particular response; some parents gave multiple responses within categories.

²Clopper-Pearson exact confidence intervals.

³"Haven't gotten around to it" (n = 7); "forgot" (n = 3); "don't know" (n = 2); "too busy" (n = 1).

⁴Outreach methods consisted of mailed pamphlet with cover letter (4th-6th grade reading level), phone call and pamphlet, or home visit and pamphlet.

⁵16 of the 17 received a pamphlet and letter; one received a telephone call.

⁶Received pamphlet and letter.

visits, the very outreach strategies that apparently had not succeeded in informing or motivating the persons giving the suggestions. When asked which was the *best* way to inform parents, the majority—regardless of the specific outreach method they themselves had received—said they preferred receiving outreach materials by mail. We conclude that a major educational effort would be beneficial but that it needed to be presented through a variety of venues including social services offices, health clinics, schools, and public places, as well as through mass media.

Nineteen parents (17%) suggested making changes in the health care system that included expanding clinic hours, increasing the availability of providers and locations, and improving the EPSDT transportation system.

“New” users’ reasons for using EPSDT services. The 30 new users were asked to give their reasons for seeking well-child checkups. Although these parents were nonusers prior to outreach, that is, their children were overdue for checkups, at the time of the interview, 29 (97%) indicated that checkups are needed to uncover hidden problems or prevent further problems and that children need checkups even when well.

Twenty-four (80%) of the 30 parents remembered the specific post-outreach checkup and gave a reason for deciding to use EPSDT services at that time. When the outreach effort reminded them that their children were overdue for care, 13 (54%) of the 24 simply agreed that it was time for a checkup. Seven (29%) said they were concerned about a specific health problem that they thought needed medical attention, and four said they were facing the need to provide documentation of a checkup for school or day care.

Barriers encountered by “new” users. All 30 parents were asked about their encounters with the health care system; the 24 who remembered the specific post-outreach checkup were asked to respond regarding that checkup, and the six who did not remember were asked to respond regarding their experiences in general. Twenty-three (77%) parents used public health clinics; the rest used private physicians. While 13 parents said they did not encounter any difficulties in using the health care system, 17 (57%) described specific difficulties in access to care and in the quality of care received.

These 17 parents reported that access to the health care services, which were in short supply, was limited because of problems in scheduling appointments and a limited choice of providers (table 3). They expressed concerns about fragmentation of care between public health clinics for well-child care and private physicians for illness care. They cited difficulties in obtaining care at times when they could bring their children in for care. One parent described an unpleasant experience in trying to change the time of an appointment. After these parents succeeded in making appointments, they had problems in arranging transportation; some lived in very remote rural areas. All parents were given out-

Table 3. Barriers To Use of EPSDT and Health Care Services Identified by 30 Parents.

Category/Barrier	Number of parents	Percent of Sample ¹
Health care system barriers.....	17	57
Access to health care system	8	27
Transportation difficulties.....	5	17
Appointment scheduling difficulties.....	4	13
Limited availability of providers.....	3	10
Quality of experience in health care system	16	53
Long waiting room times.....	10	33
Dissatisfaction with medical care provided.....	6	20
Dissatisfaction with interpersonal interactions	5	17
No barriers	13	43

¹Nonprobability sample; confidence intervals not calculated.

reach information about transportation assistance, but none received such assistance; one mother said she was embarrassed to ask for help with transportation. In the sample of new users as a whole, the parents reported spending on average 16 minutes ($sd = 11.5$) traveling about eight miles ($s.d. = 7.1$) one way to get to the health care site, though at least one parent reported spending up to 60 minutes traveling 30 miles one way.

Once at the health care site, whether public or private, these parents surmounted other barriers (Table 3). They reported having to wait on average 43 minutes ($sd = 33.5$) in the waiting room before being seen. Although the majority said they were treated with respect by all health care and ancillary personnel (83%), that they were able to ask questions (78%), and that they received understandable answers (70%), a number of parents had negative experiences. Eight parents (27%) cited specific incidents that caused them to be dissatisfied with the quality of medical care provided, the interpersonal aspects associated with obtaining care, or both. For example, one mother emotionally described an experience of a provider apparently not believing her report of the child’s previously elevated lead level, done elsewhere, and denying her request for follow-up of the lead level. Another mother was upset because the EPSDT screening provider referred her child for treatment at a health agency that, as she learned when she arrived for the appointment, would not serve Medicaid clients. Five parents said they received inadequate explanations or education about their children’s health care needs.

“New” users’ suggestions for making the EPSDT Program easier to use. These suggestions for making the program easier to use paralleled the barriers to use identified by the nonusers. The 13 parents who experienced no difficul-

ties gave no suggestions. The 17 who experienced difficulties each suggested that the specific health system barrier that they had had to overcome should be removed. Three parents also suggested the use of mailed appointment reminders, and one suggested changes in Medicaid eligibility requirements. One mother, apparently resigned to long waiting-room times, suggested that snacks be provided if the wait is excessive.

Limitations. As in all studies involving interviews, this study is limited by the degree of rapport established at the interview and the extent to which those interviewed provided truthful and comprehensive answers to the questions posed. For this study, considerable attention was paid to training public health nurses, already skilled in working with parents of low socioeconomic status, to conduct the interviews in a nonthreatening manner to elicit as much information as possible. (Though not viable for this study, using trained parent interviewers is an option worth testing.) Despite the extensive training and reliability testing, the depth of information collected varied from parent to parent, from nurse to nurse, and from day to day, depending on conditions; for example, a mother whose child began crying during an interview was less likely to give comprehensive answers.

Because the interview guides were not identical, “new” users were asked more details than nonusers. Thus the findings of this study should not be viewed as including all possible answers that parents might have given to the interview questions. Further, the findings of this study apply to parents who were eligible for specific outreach efforts in six rural counties in North Carolina. The characteristics of these parents and counties, described in this paper, should be considered when assessing the potential relevance of these findings to other populations.

Discussion

The parents in this study confirmed that making a program “free” is not sufficient to ensure continued use of preventive health care services for children of low-income families. “Free” is a relative term implying that finances are the only costs that families consider in deciding whether or not to use health services. The data from this study indicate that other costs are involved.

The findings of this study are particularly relevant in view of the current administration’s priority to improve child health by expanding access to preventive health care services. This study highlights the fact that knowledge of a free program may not be sufficient to ensure use, corroborating the results of a recent study of underimmunization of low-income urban infants, and extending them to this study’s rural population and to a wider range of preventive health care services²⁷. The low-income parents in our study described life situations that were challenging and complex; it was difficult for them to mobilize resources to obtain

health care services, even if those services were free. The interconnected reasons that these parents gave for using or not using EPSDT services were consistent with findings from previous research regarding low-income families’ decisions to use health care services, which suggested that such families had goals that competed with health care needs^{28,29}; that, in view of other pressing needs, they accorded a lower priority to health care³⁰; and that, especially in single-parent homes³¹, many had difficulty coping with the stresses of everyday living.

Parents coping with poverty-level conditions in rural areas experienced numerous difficulties in obtaining “free” EPSDT services. Despite state and county efforts to recruit physicians^{23,24}, parents had difficulty locating providers who participated in the EPSDT Program; some parents had to change providers in order to obtain EPSDT services. Many also had problems getting appointments within a reasonable time; some lost Medicaid eligibility before an appointment became available. In addition, it was difficult for parents to coordinate appointments with other family needs, including child care. Once the parents successfully negotiated these barriers and received EPSDT services, some of them encountered long waiting-room delays. Some also experienced interpersonal interactions that they thought showed a lack of respect or concern for them or their children and that caused them to question the quality of care they received. Some parents had to travel long distances to health-care facilities, as is common for rural residents³². Even though the transportation assistance component of the EPSDT Program should have eliminated barriers to travel, parents still reported having difficulties with transportation. In these rural counties, transportation assistance varied from county to county. Some counties had minibuses that provided transportation; others had procedures for mileage reimbursement (for example, for use of a neighbor’s or relative’s car). Evidently these procedures did not work well for some families.

Instead of current approaches that focus on simply informing or reminding parents of the availability of the program, outreach strategies may need to do a better job of conveying the tangible benefits of using the EPSDT Program. Examples of tangible benefits are such things as eyeglasses, medicines, and reports of immunizations or physical exams required for school or day care. Public agencies also might consider providing tangible rewards for using EPSDT. Other studies have shown that material or monetary rewards or incentives can be useful in encouraging health care use^{33,34}. If effective, such rewards can be less expensive than the personnel time involved in many outreach efforts.

Since many parents identified structural barriers to using a program specifically designed to eliminate these barriers, efforts to change people’s attitudes about the benefits of preventive health programs—even by the use of tangible rewards—may not prove adequate. Parent-focused outreach efforts should be linked to system-focused approaches that

make such programs more user-friendly and minimize the expenditure of time and energy required to obtain care.

The structural barriers that these parents identified are not new. The parents confirmed from their personal perspectives that (a) health departments constrained by their budgets have limited clinic hours and staffing; (b) many private providers do not provide EPSDT services; (c) the states provided inadequate appointment-making assistance while transportation assistance may not be coordinated with the health care; (d) loss of Medicaid eligibility disrupts care; and (e) health care encounters perceived as negative may act as deterrents to care. The fact that these barriers are consistent with what health professionals already know should not discourage action. With the national debate on health care reform, now is the time to act and to influence policy.

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