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ABSTRACT

These three booklets present information about selected aspects of the Medicaid Early and Periodic Screening Diagnosis and Treatment (EPSDT) program. A brief history of the development of the EPSDT program, a description of administrative structure at the national, state and local levels, and a description of the lifestyle typical of many EPSDT clients and some of their experiences with health services are provided. (Author/RH)

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A BRIEF HISTORY OF THE MEDICAID EARLY AND PERIODIC SCREENING DIAGNOSIS AND TREATMENT PROGRAM

EPSDT

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SPECIAL NOTE

Since the Child Health Assessment Act of 1977 (CHAP) is currently pending in Congress, the requirements of this new legislation have been reflected in the final editing of this document.

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ERIC

CONTENTS

Introduction

Section I The Origins of EPSDT

Section II What Must the States do to Implement EPSDT?

Section III Some Issues Faced by EPSDT

Section IV The Future of EPSDT

Section V Questions and Answers

NOTE TO THE READER

Medicaid programs can vary among states. Each state establishes its own criteria of eligibility and defines its own package of services within federal guidelines. This booklet attempts to discuss some features of the Medicaid Early and Periodic Screening Diagnosis and Treatment program which are common to all states and to illustrate some variations in their implementation.

Although the term EPSDT is used throughout the booklet, the programs which provide periodic child health screening, diagnosis, and treatment may have different names in different states (e.g., Child Health Assurance Program—CHAP—in New York; Medi-Check in Illinois; Project Health in Michigan, etc.).

5

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INTRODUCTION

This booklet presents a brief history of the development of Medicaid's Early and Periodic Screening Diagnosis and Treatment (EPSDT) program.

EPSDT is one of America's most far reaching publicly financed child health programs. Designed to provide for the detection and treatment of health problems of children and youth (to age 21) in Medicaid-eligible families, the program emphasizes outreach, follow-up, and transportation arrangements to make it easier for eligible children and youth to participate.

This booklet is designed for EPSDT workers, their supervisors, and program administrators. It explains how the program developed, discusses some of the problems EPSDT has encountered, and the course it may follow in the future.

SECTION I

THE ORIGINS OF EPSDT

OVERVIEW OF EVENTS LEADING TO EPSDT

The following timeline highlights key events leading to the enactment of EPSDT. The rest of this section discusses each event in detail.

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A TIMELINE OF MATERNAL AND CHILD HEALTH ACTIVITIES LEADING TO EPSDT 1935-1975

1935

The Social Security Act provides cash assistance payments to families with dependent children. Title V of this act provides grants-in-aid for maternal and child health and crippled children's programs.

WORLD WAR II

The Emergency Maternity and Infant Care (EMIC) program is established to meet the maternal and infant care needs of servicemen's dependents.

1950

Amendments to the Social Security Act provide federal matching funds to the states to help meet the cost of medical care for public assistance recipients.

1960

The Kerr-Mills Act provides the first program of comprehensive medical care for the aged. The 1960's see an expansion of Title V programs to include federal grants for local projects.

1965

Medicare and Medicaid (TitlesXVIII and XIX of the Social Security Act) finance medical care for the elderly and the eligibie poor.

1967

An Amendment to Title XIX of the Social Security Act requires states to cover Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services for all Medicaid eligibles under the age of 21.

1972

States are required to implement EPSDT or face a penalty of one percent of the federal share of their AFDC budgets for every quarter in which they have not complied with EPSDT penalty regulations.

NOW

EPSDT programs are underway and problems of implementation are being worked out on state and local levels to comply with federal regulations.

DETAILS OF THE EVENTS LEADING TO EPSDT

1935

The Social Security Act provides cash assistance to certain categories of the needy and Grants-in-Aid for maternal and child health and crippled children's programs.

In 1935 the Social Security Act established a cash assistance program for the aged, the blind, and families with dependent children. This was the first major federal program to provide cash payments to indigent and low-income people. Some of these payments were to be used for medical care. Over the years, amendments to the Social Security Act have modified the form of payment, the extent of benefits, and the range of eligibility; Medicaid and its EPSDT component are among the most recent of these modifications.

Originally, benefits under the Social Security Act were limited to cash payments to the person in need. The recipient decided how to spend this money. While some of the money was intended for health services, many welfare recipients never sought needed medical care because they considered it a luxury. If no immediate or visible health problem existed, recipients of cash assistance tended to use all of the money for basic maintenance needs, rather than keep some funds for health services. In some families with dependent children, medical care was sought only after children's health problems became severe. Thus, the direct cash method of paying for medical services did not ensure that adequate health care was sought or obtained. A system of payment for service was needed which would encourage eligible people to obtain preventive and routine health care as well as treatment for emergencies.

In addition to cash payments, the Social Security Act of 1935 established a program for crippled children which enabled each state to extend and improve its services for locating such children and provide needed medical, surgical, and corrective services. Although the outreach aspect of these "Title V" programs was not actively pursued, some health screening services were provided as part of the registration procedure. Other steps to provide preventive health care under Title V included supervision of maternity clinics and hospitals and the establishment of "well child conferences" to provide a forum for discussing the issues of maternal and child health.

WW II — Emergency Maternal and Infant Care (EMIC) program.

World War II created the need for expanded health service delivery. The families of servicemen who moved to small towns near army bases placed a strain on available child health services leading to the creation of the Emergency Maternity and Infant Care (EMIC) program.

EMIC was the largest public health undertaking in America up to that time. It was completely funded by federal monies given to the states to provide preventive and treatment services for wives and children of lower rank servicemen. Although EMIC was not continued after the war, it demonstrated the feasibility of federal-state cooperation in health service delivery.

1950 — Social Security amendments provide federal matching funds for medical care.

During the late 1940's, the federal government was under pressure to provide states with funds to directly reimburse health care providers for their services to public assistance recipients. In 1950, the Social Security Act was amended to provide federal matching funds to states for medical care payments to providers on an individual case basis. Between 1950 and 1956 only twenty states adopted this form of payment, but in 1956 benefits were expanded, the percent of federal matching increased, and administrative procedures were modified, making it easier for the states to participate. Because of these changes several states took the opportunity to begin subsidized medical care to public assistance recipients while other states expanded their existing programs. In 1958, the federal government made funds for medical care available to the states for all federally eligible welfare recipients regardless of whether they actually received such care. This simplified administrative procedures, increased the amount of money available to the states, and was a further inducement for states to broaden their subsidized medical care benefits.

1960 Expanded programs for children and medical assistance for the aged are established

The 1960's saw the development of a number of federally funded health programs for children. Established under Title V of the Social Security Act, the programs were expanded to include federal grants for local projects in maternity and infant care (1963), children and youth (1965), and dental and intensive infant care (1968). Local health services were also provided under the auspices of the Office of Economic Opportunity (OEO) which funded neighborhood health centers and services for children under the Headstart program.

By 1960, discussion of the need for comprehensive health services focused on the plight of the aged. Congressional concern for older Americans unable to afford adequate health care was high, and the debate about how to finance health care for the aged led to the enactment of the Kerr-Mills amendments to the Social Security Act. While Kerr-Mills did not provide medical care benefits to all older Americans, it did create a new public assistance category: Medical Assistance for the Aged (MAA). In states choosing to enact MAA programs, older persons whose incomes were too high to qualify for cash assistance payments under public welfare, and too low for them to afford adequate medical care, were eligible for some federal subsidization of their medical expenses.

Response to the Kerr-Mills Act was only lukewarm. A number of states feared the drain it would put on their treasuries, and many of the aged who qualified for the program did not participate because they were uncomfortable with the red tape involved in proving eligibility. Nevertheless, the Kerr-Mills Act established a precedent of providing comprehensive health services to a population in need and laid the foundation of a medical assistance program which was the model for Medicaid and its EPSDT component.

1965 Amendments to the Social Security Act establish Medicare for the aged, and Medicaid for public assistance recipients.

In 1965, Congress passed a set of amendments to the Social Security Act. Title XVIII of these amendments established a program to provide health insurance for the aged. This

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program (commonly known as Medicare) was to be administered through the Social Security system. Title XIX of the Social Security Act established another new program called Medicaid—an extension of the Kerr-Mills Act—to provide health services to certain categories of the poor. Medicaid is the "parent" program of which EPSDT is a part; a clear picture of Medicaid can help you understand EPSDT.

WHAT IS MEDICAID?

Medicaid is a cooperative federal-state program providing payment of medical expenses for eligible persons. Eligibility includes persons whose incomes are low enough to meet eligibility requirements set by the states and who are over 65, blind, otherwise disabled, or members of a family with dependent children. Federal legislation specifies the content of the minimum benefit package Medicaid must provide. The federal government also contributes to the cost of as many of the specified optional medical services as the state is willing to include in its benefit package. Medicaid is jointly financed by the federal and state governments from general revenue funds. Implementation varies from state to state: some states have more elaborate and costly sets of benefits than do others; in some states, local governments share in the cost.

Medicaid is administered on the federal level by The Medicaid Bureau (MMB) of the Department of Health, Education and Welfare's Health Care Financing Administration, and by departments of public welfare or social services on the state level. In some states the program may be lodged in a department of health or in a comprehensive human service agency.

The federal government requires all state Medicaid plans to cover welfare (AFDC) recipients and most Supplemental Security Income (SSI) recipients, and reimburses states for a share of the cost of their health care. The federal government will also reimburse states for a share of the cost of health care for some other groups of people the states choose to cover under their Medicaid plans, e.g., other SSI recipients and members of families with dependent children who do not qualify for cash assistance but whose incomes are too low for them to purchase adequate medical care. (These people are sometimes referred to as "medically indigent" or "medically needy.") Because of this federal-state relationship, the Medicaid program reflects both federal regulations and the results of action taken by the states to implement them. States establish eligibility criteria, the kind and extent

of benefits, and the administrative mechanism for the program. The federal government issues regulations and guidelines for state programs, reimburses states, and monitors state programs to be sure they follow federal regulations.

WHO IS ELIGIBLE FOR MEDICAID?

Eligibility for Medicaid varies from state to state, but it always includes persons who are receiving public assistance payments from the Aid for Dependent Children (AFDC) program and most of the aged, blind, and disabled adults who receive Supplemental Security Income (SSI) or a state supplement to that program. A few states, however, have more stringent eligibility standards for Medicaid than the federal eligibility standards set for SSI.

In addition, some states include the "medically indigent" or medically needy" in their medical assistance plans. These are people whose incomes or assets are too high for them to receive cash assistance, but who cannot afford to pay their medical expenses. Each state determines the maximum income and resource level at which persons qualify for cash assistance and Medicaid.

In addition, states may choose to pay for Medicaid services for other persons not eligible for federal assistance. In that case, the state must pay the entire cost.

1967

Social Security amendments establish EPSDT: an expansion of Medicaid services for children.

In 1967, Congress passed additional amendments to the Social Security Act setting up a program of early and periodic health screening, diagnosis, and treatment for Medicaid eligible children.

Unlike previous federal medical assistance programs, EPSDT is more than a program which simply pays for health care that eligible individuals seek when they are sick. EPSDT provides for preventive health care that can identify problems before they become severe. Furthermore, under EPSDT, preventive services and necessary follow-up, diagnosis, and treatment must be provided periodically as long as the individual is eligible for Medicaid. EPSDT also provides supportive services which make it easier for clients to take part in the program.

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1974

States are required to implement EPSDT or face paying a penalty equal to one percent of the federal share of their Aid for Dependent Children (AFDC) budget for each quarter in which they are not in compliance with federal EPSDT penalty regulations.

Although legislation authorizing the EPSDT program was enacted in 1967, the program was not put into effect for several years. Some states thought the program placed an additional burden on already overworked social services staffs, and that health care resources were inadequate to meet the needs of all EPSDT-eligible persons. Welfare rights and welfare recipient groups helped get EPSDT underway when they brought suit in court against state and federal governments for failing to begin EPSDT.

Federal regulations for EPSDT were published in 1971. They were designed to help the states establish EPSDT programs by allowing them to begin with services for children under six years of age and later phase in older children and youth up to age twenty-one. In 1972, amendments were added to the Social Security Act specifying that any state that failed to inform all AFDC families about EPSDT, failed to provide screening services when requested, or failed to provide necessary follow-up diagnostic and treatment services would be penalized one percent of the federal share of its AFDC budget for any quarter in which the state was not in compliance.

NOW

EPSDT Programs are underway. The problems of implementation are being worked out on the state and local level.

Following the clear Congressional mandate to implement EPSDT represented by the penalty regulations, the Department of Health, Education and Welfare (HEW) has taken a more vigorous approach to promoting implementation of EPSDT. The strong position taken by HEW in support of EPSDT has led

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the states to find innovative ways to carry out this program, to provide preventive and comprehensive health services to eligible children and youth, and to facilitate their use of those services by providing transportation, health education, and follow-up services in support of EPSDT.

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SECTION II

WHAT MUST THE STATES DO TO IMPLEMENT EPSDT?

In order to implement EPSDT, a state must comply with federal EPSDT regulations. It must organize services, conduct outreach, provide reimbursement for health service costs, process information, conduct program evaluation, and coordinate EPSDT with other services.

COMPLY WITH EPSDT REGULATIONS

EPSDT penalty regulations require that each state make certain that:

- All AFDC families are informed at least once a year in writing of what services are available and how and where to obtain them.
- Screening is provided within 60 days of when a family requests it.
- Clients needing follow-up diagnostic and treatment services receive such services normally within 60 days of screening.
- All eligible families are provided with transportation, if necessary, to make it easier for them to participate.

ORGANIZE SERVICES

To effectively implement EPSDT, the states must design an appropriate package of screening services and decide how such services are to be delivered. EPSDT services can be provided by private physicians, in hospitals and clinics, or through publicly funded facilities such as the local health department. Any one or a combination of these providers may be used. Whatever the source of service, the state must ensure provision of the full package of screening services and must provide or arrange for diagnosis and treatment where needed.

CONDUCT OUTREACH

Outreach activities are a key to the success of EPSDT. They consist of all efforts to identify, inform, and involve eligible children and youth in EPSDT. While mailing information about EPSDT with welfare checks is a part of outreach, it is seldom enough. A more successful approach involves personal contact between EPSDT workers and potential participants. Phone calls are usually more effective than letters, and personal visits are generally more effective than phone calls. The time and effort EPSDT workers put into outreach and case contact activities can mean the difference between the success and failure of the program.

PROVIDE ASSISTANCE IN OBTAINING EPSDT SERVICES

Outreach alone is not enough. EPSDT workers must assist participants in finding providers of health service (physicians, dentists, clinics, health departments, etc.) to meet their needs. Assistance should be provided in scheduling appointments with these providers and in helping clients to keep these appointments through provision of transportation, assistance with child care arrangements, etc. If appointments are missed, EPSDT workers should follow up with the clients to arrange new appointments.

PROVIDE REIMBURSEMENT FOR PROGRAM COSTS

Providers of health service (physicians, dentists, clinics, health departments, etc.) should be encouraged to participate and are reimbursed by the state for their services. A reimbursement system whereby providers record information specifically related to EPSDT service delivery at the same time and on the same form as requests for reimbursement may make follow-up and evaluation easier and more effective.

PROCESS INFORMATION

Records of each participating child should be maintained to permit follow-up and ensure that the individual child receives

a continuous and coordinated set of services. Records also permit evaluation of program effectiveness, health service delivery, and payment processing. EPSDT recordkeeping may be complicated by the fact that over time families may shift in and out of eligibility. Accurate records, however, must be maintained to document compliance with federal regulations and to assess and plan for the health maintenance and treatment needs of participating children and youth.

CONDUCT PROGRAM EVALUATION

Criteria for evaluating EPSDT services are being developed as the program grows. While the initial emphasis has been on screening as many children as possible, state programs have begun to concentrate on ensuring provision of a wide range of treatment services. As states develop more efficient reporting systems, attention can be shifted from merely increasing numbers of participants to a focus on improving the outcomes of EPSDT services. Programs can then be redesigned or modified to maximize their positive impact on the health of eligible children and youth.

COORDINATE EPSDT WITH OTHER CHILD SERVICES

There are a number of other child health and welfare services that exist in the states. To avoid duplication and to provide comprehensive services to the child, EPSDT must be coordinated with the activities of these programs. This means that administrators of EPSDT programs and their staffs should know about other child health and welfare services in their community (maternal and infant care programs, children and youth programs, neighborhood health centers, etc.)—what they do, and whom to contact and work with to plan for coordination of services.

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SECTION III

ISSUES FACED BY EPSDT

A number of issues have emerged as EPSDT has developed. While some of these issues involve problems which are beyond the power of local EPSDT workers to solve, they do highlight some of the factors which may shape the future of the EPSDT program.

- EPSDT was developed at a time when the federal government was expanding its support for health service programs. If money for health service programs becomes tighter, those who hold the purse-strings may develop more control over service delivery programs such as EPSDT. This could mean that program priorities will be determined more by financial concerns than client needs.
- Limited availability of health services, particularly preventive health services for children, makes such services difficult for Medicaid eligible families to obtain. The pattern of health care in the United States is based largely on private physicians and hospitals. Available services may be either inadequate for the increased demand produced by Medicaid, or not located in areas convenient for Medicaid recipients.
- Financing is not automatically linked to appropriate or effective organization, delivery, and utilization of services. EPSDT programs bring providers of health services, their clients, and providers of funds together in one program. Health services providers are often unhappy with the amount of reimbursement and delays in reimbursement for their services; agencies who pay the bills want to keep costs down, enforce standards for providers, and eliminate fiscal fraud. Clients want the best available service and the least amount of trouble obtaining it.

  EPSDT needs to reconcile these various goals, ensure accountability by health service providers,

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and maintain good relations between providers and their clients. This is complicated by the fact that administrative and fiscal responsibility for EPSDT is shared between federal and state government, while responsibility for program operations usually rests with the state which coordinates local program implementation.

- Program outreach, essential to the effectiveness of EPSDT, may strain the capacity of many administering agencies. Because part of EPSDT's mission is to improve the way clients use medical services, the program needs to develop effective outreach mechanisms. Many people need help in learning how to utilize health care services. Prospective patients and their families should receive clear, personal, and relevant health education and help in getting to and using health services. Since this may increase the responsibilities of existing staff, federal matching funds are available at a rate of 75 percent for local workers providing EPSDT health-related support services. If states do not take advantage of these matching funds to expand staff, there may not be enough staff to do the job of providing effective EPSDT services.

- Follow-up to ensure that needed health services are obtained is necessary for effective service delivery. Satisfactory follow-up is difficult to guarantee. Some EPSDT clients may not seek needed treatment, and for many clients, the problems of case management are compounded because services must be coordinated among a number of health care providers.

SECTION IV

THE FUTURE OF EPSDT

EPSDT is now being implemented. Initial reports indicate that it is effective both in finding children in need of health care, and ensuring that they receive it. For the most part, screening is proceeding well and more and more states are turning their attention to making sure that treatment and follow-up are provided. Problems in getting families to keep appointments and obtain needed follow-up care for their children are common. In some areas, recruiting treatment providers who accept EPSDT clients is also a problem. Some providers are not attracted by the levels and methods of reimbursement; others already have a full practice and do not want additional patients. Rural areas present particularly difficult problems of availability and accessibility of providers of EPSDT services. Obtaining dental care has been especially difficult because of limited numbers of participating dentists in locations where they are needed and because of the high cost of dental care.

Some states have found it difficult to develop an effective system for information retrieval, storage, and utilization, especially when the shifting eligibility of some families makes it difficult to maintain updated records and to assure continuation of necessary care and periodic services. However, many states have shown that a variety of innovative solutions to serve delivery problems can be found by staffs which are committed to the EPSDT program. From the experience of EPSDT so far, it seems clear than an emphasis on prevention will continue to set the tone of health services for children.

SECTION V

QUESTIONS AND ANSWERS

EPSDT workers may be asked to provide information about the program. The following questions are typical of some of the things people might want to know about EPSDT. Short answers to these questions, and references to sections in this booklet where the answers are discussed in greater detail, appear on pages 18-19.

QUESTIONS ABOUT EPSDT

1) What is "new" about EPSDT?

2) What is Medicaid? Whom does it serve?

3) How is the EPSDT program related to Medicaid?

4) What are seven things the state should do to implement an EPSDT program?

5) What are four issues which have been highlighted by EPSDT programs?

ANSWERS

1) EPSDT is new because
   —it focuses on comprehensive and preventive health care;
   —it provides health support services, including health education, transportation, and case management.

(If you could not answer this question, refer back to page 8-9 in the booklet.)

2) Medicaid is a state/federal program providing financial assistance for health care services for certain low income persons.

(If you could not answer this question, refer back to pages 6-7 in the booklet.)

3) EPSDT is a required service under the Medicaid program. Its focus is on providing periodic preventive health care to children and youth (to age 21) from eligible low income families.

(If you could not answer this question, refer back to page 1 of this booklet.)

4) To implement an EPSDT program, each state needs to:
   (1) comply with EPSDT regulations;
   (2) organize services;
   (3) conduct outreach and ensure that screening, diagnostic, and treatment services are available;
   (4) provide reimbursement to health service providers for program costs;
   (5) record, store, and process information;
   (6) coordinate with other child services;
   (7) conduct program evaluation.

(If you could not answer this question, refer back to pages 10-12 in the booklet.)

5) Issues highlighted by EPSDT include the following:

   (1) Financing of EPSDT services does not automatically lead to appropriate or effective utilization and delivery of health care.
   (2) It is administratively complicated.
   (3) Health services, particularly comprehensive preventive services for children, are unevenly distributed and

sometimes difficult for low income people to locate or obtain.

(4) EPSDT may place a strain on already overworked social services staffs unless states take advantage of federal 75 percent matching funds to hire, train, and supervise EPSDT workers.

(If you could not answer this question, refer back to pages 13-14 in the booklet.)

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The following sources were particularly helpful in preparing this booklet. They can provide the interested reader with more details about the development of EPSDT.

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24

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EPSDT: ORGANIZATION

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THE ADMINISTRATIVE ORGANIZATION OF EPSDT

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CONTENTS

Introduction

Section I EPSDT: The National Level

Section II EPSDT: The State Level

Section III EPSDT: The Local Level

Section IV Questions and Answers

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NOTE TO THE READER

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30

INTRODUCTION

This booklet describes the distribution of administrative responsibility for the Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. Written for EPSDT workers, their supervisors, and administrators, it provides an overview of EPSDT as a national, state, and local program, and describes some of the agencies and programs with which EPSDT cooperates.

SECTION I

EPSDT—THE NATIONAL LEVEL

WHO IS RESPONSIBLE FOR EPSDT?

The ultimate responsibility for EPSDT rests with the President and the Congress. Together they define national policy and set priorities for federal programs. While Congress passes legislation and allocates funds to establish and implement programs such as EPSDT, the President supports or discourages action taken by Congress and by administrative agencies.

EPSDT is administered by The Medicaid Bureau (MMB). Until 1977, MMB was part of the Social and Rehabilitation Service; now, it is part of the Health Care Financing Administration (HCFA), a division of the Department of Health, Education and Welfare (HEW). HCFA issues guidelines and regulations to the states on the scope of various components and on methods for operating their EPSDT programs, monitors state programs to assure compliance with federal regulations, and provides them with technical assistance.

WHAT GROUPS ARE INTERESTED IN EPSDT?

A number of organizations are concerned with EPSDT. Within HEW, the Public Health Service and the Office of Child

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Development carry on EPSDT-related activities. Citizen groups which support the rights of welfare recipients and the interests of children have successfully brought suit in court to hasten EPSDT's implementation, and have maintained their interest in the program. From the outset, professional associations of health care providers have participated in the development of the program and have been asked to collaborate in the preparation of guides on implementation of various aspects of EPSDT.

WHAT ARE THE LESSONS OF EPSDT FOR OTHER PROGRAMS?

Though a relatively new program, ESPDT provides lessons useful for consideration in the shaping of future health service programs.

- **The importance of careful planning before** beginning large-scale service delivery programs is evident from some of the early difficulties encountered by EPSDT. Its subsequent history, however, shows that creative program implementation can solve problems and minimize the chance of their recurrence.

- **Close federal, state, and local cooperation** are essential for the success of such programs.

- **Citizen's groups can be influential** in promoting such programs through legislative, judicial, and administrative channels.

- **Obtaining a high rate of client participation** requires outreach and follow-up activities in health care programs for low income clients.

- **Data collection, storage, and retrieval systems** are needed to handle the data processing tasks of large scale health service programs.

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SECTION II

EPSDT: THE STATE LEVEL

ADMINISTRATIVE MODELS OF EPSDT IN THE STATES

EPSDT is a component of the Medicaid program. The law requires that a single state agency be responsible for administering Medicaid, although it can contract with other agencies to carry out some of the program's functions. The scope of the Medicaid program in each state determines the limits of eligibility, coverage of services, and the methods for reimbursing providers of health services to Medicaid clients in that state. Within federal minimum requirements, each state's program can differ in the services it offers, but each state is responsible for monitoring and evaluating program implementation at the local level. While Medicaid programs differ from state to state, three distinct organizational models can be identified: the program may be administered by the state welfare department; by the state health department; or by an agency combining both health and welfare functions.

The Welfare Model: In most states, EPSDT is administered by the welfare department. This department usually provides casefinding, transportation, and case management services, and subcontracts the provision of health care services to other public agencies, voluntary organizations, private groups, or individual providers. For example, a state welfare department may contract with the state health department for providing the screening component of EPSDT, since the health department has the facilities and expertise to furnish this service. Another frequently subcontracted task is reimbursement of providers. Private insurance companies such as Blue Shield which have the equipment and trained staff may be engaged by the state to perform this task.

The Health Department Model: In some states, the state department of health is responsible for administering EPSDT. The job of determining eligibility, however, rests with the

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welfare department, since eligibility for EPSDT is dependent on eligibility for public assistance.

The Combined Health and Welfare Model: Where states have included health and welfare departments under one organizational umbrella, EPSDT is administered by this combined agency. While the functions of health and welfare may remain in separate units, the combined structure makes it easier to coordinate their activities without complicated interorganizational relationships.

CENTRAL & DECENTRALIZED ADMINISTRATION OF EPSDT

Generally, Medicaid is administered from a central office. Because centrally administered programs may not be sensitive to the special service requirements of diverse client populations, regional and local offices in some states have been given responsibility for adapting programs to meet the needs of local populations. Such locally administered programs are likely to be more effective than centrally administered programs. Some may encompass a number of counties, particularly in sparsely populated rural areas, while in more crowded urban areas a region may consist of only one city or even part of a city.

STAFFING PATTERNS IN EPSDT

In states where few people are directly involved in implementing Medicaid and EPSDT, the job of identifying and informing eligibles is handled by eligibility workers in the welfare department. This is usually a task which must be done in addition to their other duties and leaves them little time to offer supportive services which would facilitate client participation.

Since the emphasis of EPSDT has shifted from informing eligibles to actively reaching out to them and promoting participation, this staffing pattern is not adequate. Expanded staff and a revised administrative structure are needed. Therefore, staff assigned especially to EPSDT are being hired at the local level in a number of states. They are responsible for assuring that adequate arrangements are made for needed health care and that such care is provided.

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Seventy-five percent of the salary for such staff and the cost of their training, travel, and supervision can be reimbursed from federal matching funds.

THE STATE AS A SERVICE PROVIDER

States may provide screening services but state health departments usually are not equipped to operate large scale diagnosis and treatment programs. These aspects of EPSDT are usually carried out by other public and private health service providers.

Even if a state has no direct part in providing health services it still remains responsible for ensuring that all eligible children receive the complete range of EPSDT services.

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HOW IS EPSDT ORGANIZED IN YOUR STATE

We have described several organizational models of EPSDT. On the following chart you can fill in notes and comments about the EPSDT program in your state.

1. Who has administrative responsibility for EPSDT in your state?

2. What agencies cooperate in the operation of EPSDT?

3. With whom does your state subcontract for EPSDT services?

4. Who provides EPSDT services in your state?

5. How is EPSDT administered at the local level in your state? In your local community?

6. What are the names of people in other agencies with whom you work on EPSDT?

NAME: AGENCY:

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SECTION III

EPSDT: THE LOCAL LEVEL

The local EPSDT agency is responsible for case identification and management. By having direct contact with clients and handling the paperwork entailed in these interactions, the local agency helps clients and providers establish an ongoing relationship. Such a relationship can help ensure continuity of care and preventive as well as remedial health services for eligible children. While some state EPSDT agencies carry out screening at the local level, few, if any, directly provide treatment. The EPSDT program mandates that ongoing treatment be available and that Medicaid pay for it whether it is received from public or private sources. The intent of the program is that Medicaid-eligible children obtain comprehensive initial health care and have access to continuing care as needed. EPSDT collaborates with the public and private sectors so that all eligible children can receive needed health services.

In many communities, there are a number of organizations, agencies, and programs furnishing services to EPSDT eligible clients. Since EPSDT workers may have to coordinate service delivery activities with these agencies, they should know about them. Some are publicly supported from tax revenues, others are private. Some provide health services, some provide social services, and some provide a mixture of health and social services. Most of the programs concentrate their activities in selected geographic areas or with specific client populations. It is important to know where these programs operate and who they serve.

PUBLICLY-SUPPORTED HEALTH PROVIDERS

Publicly supported providers of health services may receive their funds from federal, state, or local governments. Examples of such programs are:

Children and Youth Programs (C & Y): Programs established to provide comprehensive health care for a limited number of

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children and youth furnish a variety of services ranging from diagnosis and treatment to nutritional and psychological counseling. Dental and nursing care are also provided, as are the specialized services of a number of health and mental health consultants. Services to children and youth in these programs are either centrally located in a clinic or hospital or are provided through a network of satellite offices.

Maternal and Infant Care Programs(M & I): These programs provide care for eligible expectant mothers and their infant children. They are often coordinated with C & Y programs. Supported by federal funds allocated under Title V of the Social Security Act, C & Y and M & I programs serve clients in low income ares. The clients of these programs are likely to include people eligible for EPSDT.

Community Health Centers: Community health centers include neighborhood health centers, part of the services originally offered by the Office of Economic Opportunity (OEO), and family health centers established under more recent federal public health programs. They provide health care to members of low-income and Medicaid-eligible families in selected areas.

Crippled Children's Services: Supported by Title V funds and administered by the state health department, crippled children's services focus on handicapping conditions including vision, speech, and hearing loss. Services may be provided in a hospital out-patient department, rehabilitation center, or through private non-profit organizations. In this program, children are referred to sources of care by a physician, and funds are provided on a federal-state matching basis.

Public Hospitals: Public hospitals, including municipal or county hospitals, provide care both for inpatients (those who remain in the hospital overnight) and for outpatients (those who visit the hospital to receive care but stay at home). Subsidized by public revenues, they provide services free to the indigent but are reimbursed for Medicaid eligible patients. While public hospitals remain a major health service resource in the com-

ERIC

munity, they often do not have sufficient resources to meet the extensive demand for their services.

School Health Services: School health services usually consist of vision, hearing, and speech screening. If a handicapping condition is severe, the schools usually refer children for treatment which can be paid for by the crippled children's program. The schools also offer remedial and special education classes and counseling services.

PRIVATE HEALTH PROVIDERS

Private Practitioners: The majority of health services in the United States are provided by private practitioners working alone or in groups. They are usually paid a separate fee for each service they provide.

Private Hospitals: Private hospitals may be profit-making or non-profit. Most private hospitals, like public hospitals, provide both inpatient and outpatient care. Private hospitals operate on a fee-for-service basis and are reimbursed by Medicaid for eligible patients. People unable to pay for hospital services are often referred to a public hospital. Some private hospitals receive or have received funds from public and private organizations; as a result, they are enabled or required to provide care for low-income people.

Health Maintenance Organizations: The health maintenance organization (HMO) provides comprehensive health services, including basic or primary services and some specialized or secondary services. Some HMOs have their own hospital. Like neighborhood health centers, they serve people of all ages. Clients pay a fixed monthly fee regardless of how often they use the HMO. When Medicaid clients sign up with an HMO, Medicaid will not pay for medical services received from other sources.

Medical Foundations: Medical foundations, a variation of HMOs, are organized by physicians who are usually paid a separate fee by the foundation for each service they

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provide.Clients have a wider choice of physicians available than they have in the prepaid group practice version of the HMO.

University Programs: A public or private university may offer special health services for some children. University research programs also sometimes provide services for children with selected health problems. Medical schools and university hospitals offer services similar to those of other private health providers.

SOCIAL SERVICE PROGRAMS

Since a child's health is seldom an isolated area of need, an EPSDT client may require a variety of other services. While the primary focus of the EPSDT worker's job is helping eligible clients receive EPSDT services, the worker should know about other available services.

Public providers of non-health services include the schools which maintai.. counseling and some special education programs; municipal recreation departments operating a number of activities for children and youth of all ages; public libraries and museums which offer special educational and cultural programs for children; and the courts and police which have special services designed to prevent delinquency and to help children and youth who have trouble with the law. State departments of welfare or soc al services offer protective services which focus on neglect and child abuse, homemaker services to help a family during periods when additional help in the home is needed, day care programs providing supplementary child care during part of the day, and substitute or foster care when an alternate home environment is needed.

Privately sponsored social service programs include church organized activities, ethnically oriented service agencies, recreational and community centers, special private schools, rehabilitation services. service agencies funded by non-public sources such as the community chest or red feather agencies,

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and voluntary organizations which have programs for children and youth.

A number of programs focus on the special service needs and problems of children and youth. They include crisis centers, counseling for unmarried mothers, and programs for runaway youth. These may be ongoing programs or may be established to meet the needs of a specific situation and dissolved when their task is completed. They may focus on a specific client group or problem and offer limited services, or offer a multiplicity of services to a variety of clients. The EPSDT agency should keep an updated file on service programs and the assistance they provide, and EPSDT workers should keep files on their own contacts with these programs.

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SECTION IV

QUESTIONS AND ANSWERS

The following questions and answers highlight information about the organization of EPSDT. Answers are provided to the questions referring to information presented in the booklet. You must furnish the answers to questions about EPSDT in your state. Your supervisor or the state EPSDT coordinating agency can help.

QUESTIONS

1. What role do the president and Congress play in EPSDT?

2. What federal agency has over-all administrative responsibility for EPSDT and all other health and welfare programs?

3. What agency administers EPSDT?

4. What role have citizens groups played in helping get EPSDT underway?

5. Which agencies in the state are responsible for EPSDT?

42

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6. Name three public and three private kinds of health service providers.

7. What agency has administrative responsibility for EPSDT in *your* state?

8. With whom and for what does the EPSDT administering agency subcontract in *your* state?

9. Name three public and three private kinds of providers commonly used by EPSDT in *your* state.

10. Is *your* state EPSDT program uniformly administered or does it vary locally?

11. Whom could you consult to find out more about EPSDT in *your* state?

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ANSWERS

1. The president and Congress set national priorities and are ultimately responsible for EPSDT. The Congress passes legislation and allocates funds for program implementation. The president encourages or discourages action by Congress and administrative agencies.

(If you could not answer this question, refer back to page 1 of this booklet.)

2. The U S Department of Health, Education and Welfare.

(If you could not answer this question, refer back to page 1 of this booklet.)

3. Health Care Financing Administration.

(If you could not answer this question, refer back to page 1 of this booklet.)

4. Citizens' groups have helped promote such programs through legislative, judicial, and administrative channels.

(If you could not answer this question, refer back to page 2 of this booklet.)

5. Public welfare, public health.

(If you could not answer this question, refer back to page 3 of this booklet.)

6.

Public

(a) Maternal and infant care programs
(b) Children and youth programs
(c) Crippled children's programs
(d) Community health centers
(e) Municipal and county general hospitals
(f) School health screening

Private

(a) Health maintenance organizations
(b) Private hospitals
(c) Private practitioners
(d) Medical foundations
(e) University programs

(If you could not answer this question, refer back to pages 7-10 of this booklet.)

7-11. These questions refer to EPSDT in your state. Answers can be found in the chart you completed about the EPSDT organization in your state. Refer back to this chart on page 6.

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Health Care Financing Administration
United States Department of Health, Education and Welfare

EPSDT: CLIENTS

PS 011087

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SPECIAL NOTE

Since the Child Health Assessment Act of 1977 (CHAP) is currently pending in Congress, the requirements of this new legislation have been reflected in the final editing of this document.

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THE CLIENTS OF EPSDT AND THEIR EXPERIENCE WITH MEDICAL SERVICES

This booklet was prepared by
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U.S. Department of Health, Education and Welfare
Health Care Financing Administration

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This is one of six information booklets with accompanying training materials for the Medicaid Early and Periodic Screening Diagnosis and Treatment (EPSDT) program. These materials were prepared for the United States Department of Health, Education and Welfare by the EPSDT Training Materials Development Project at The University of Michigan, a collaborative effort of the School of Public Health (Department of Medical Care Organization and Program in Maternal and Child Health) and the School of Social Work (Program for Continuing Education in the Human Services). Project Co-Directors are Eugene Feingold, Ph.D., Armand Lauffer, Ph.D., and Ruben Meyer, M.D. All products were prepared under grant number 47 P 90036/5-01 from Public Services Administration, Office of Human Development, U.S. Department of Health, Education and Welfare under authority of Section 426 of the Social Security Act.

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CONTENTS

Introduction

Section I Low Income Families and Health Services

Section II Health Practices of Families from Various Cultural Backgrounds

Section III EPSDT Outreach and Follow-up with Low Income Families

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NOTE TO THE READER

Medicaid programs can vary among states. Each state establishes its own criteria of eligibility and defines its own package of services. This booklet attempts to discuss some of the features of the Medicaid Early and Periodic Screening Diagnosis and Treatment program which are common to all states, and to illustrate some variations in their implementation.

Although the term EPSDT is used throughout the booklet, the programs providing periodic child health screening, diagnosis, and treatment may have different names in different states (e.g. Child Health Assurance Program—CHAP—in New York; Medi-Check in Illinois; Project Health in Michigan, etc.).

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INTRODUCTION

This booklet, concerning the clients of Medicaid's Early and Periodic Screening Diagnosis and Treatment (EPSDT) program, furnishes some basic information about the lifestyle typical of many EPSDT clients and some of their experiences with health services. The booklet, designed to orient EPSDT workers to issues affecting client participation, can help these workers provide outreach and follow-up services, anticipate clients' problems, and help them derive the most benefit from the program.

SECTION I

LOW INCOME FAMILIES AND HEALTH SERVICES

WHO ARE THE CLIENTS OF EPSDT?

The clients of EPSDT are children from low income Medicaid eligible families. Their living situations are often characterized by substandard housing, crowded conditions, poor nutrition, lack of money, and limited opportunities for economic advancement. These children face a greater risk of health problems than children from more affluent families. In some sections of the United States, children from such low income families have five times more emotional problems, six times more hearing defects, and seven times more visual problems than children from wealthier homes. Almost two-thirds of the children from low income families in the United States have never been to a dentist and almost half of them have not been fully immunized against preventable diseases.

Despite the health care needs of these children, their parents are not usually oriented to the idea of preventive health care and often do not seek medical or dental services unless a

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child has obvious symptoms of a problem. It is, however, these children who might benefit most from the preventive health care offered by EPSDT.

RESISTANCE TO SEEKING HEALTH CARE

The reasons for under-utilization of health care services by low income families are complicated. Lack of funds to pay for health services is not necessarily the only explanation: even when a program such as EPSDT subsidizes health care services, low income families may not take advantage of such services. It is the life situation of these families, their lack of knowledge about the importance of preventive health care, and their previous experiences with health care services that may explain why they find it difficult to participate fully in EPSDT.

The life situation of low income families. Low income families lack resources. While they must make do without many of the things that more affluent families take for granted, their lack of resources has consequences which go beyond deprivation and a lower material standard of living. People in low income families often live in a state of insecurity. The first to be laid off from the job, they cannot plan for the future because they do not know what the future will bring. Thus their orientation is directed toward the here and now, toward solving immediate problems and meeting immediate needs.

The idea of preventive health care—obtaining medical and dental examinations when there are not obvious symptoms of problems and obtaining treatment for minor problems before they become serious—runs counter to this orientation. These families may be unlikely to keep up with a program of regular periodic health examinations if no health problems are discovered. Ongoing health education is therefore needed to reinforce their understanding of the value of preventive care.

Low income families may also face a dilemma with regard to supportive services. On the one hand, they may need, and are entitled to, the services which can help them through some of their difficulties and which can help to assure their children the opportunity for a healthy productive life. On the other hand, some low income families have had experiences with programs which were supposed to help them or their children, but

which had little positive effect on their situation. Consequently they may be skeptical about the EPSDT program's effectiveness. Some of them may feel that EPSDT workers are using the program as an excuse to carry on investigative activities and may view the workers' efforts with suspicion or cynicism. EPSDT workers must try to allay these feelings and promote a positive image of the program based on an understanding of its services.

The experience of low income families with health services. Even in the best of circumstances, a visit to a physician, dentist, clinic or hospital can be upsetting. Lack of understanding about one's health care needs and uncertainty about the result of such a visit can only contribute to a patient's anxiety. One way for a patient to reduce fear and anxiety about health problems is to try to establish a friendly personal relationship with the physician, dentist, or health care worker. Modern medicine, however, often organized or practiced in ways which do not facilitate such a relationship, can leave patients and their families confused and alienated. A family may see more than one health service provider over time; several doctors, nurses, and technicians may attend a patient during a single visit, and it may be impossible to get to know any of them. The comings and goings of these men and women in white may confuse both children and their parents, and this confusion can only increase when they do not fully comprehend what is happening. Not knowing what questions to ask or not wanting to seem ignorant, low income families may not seek further explanation of matters about which they are uncertain. If health service providers assume that silence indicates understanding, the patient and family may never have their questions answered and may leave more confused and more anxious than before they arrived. Such experiences build up resistance to health services and may lead to avoidance of professional care until problems become so severe that they cannot be ignored.

The experience of health service providers with low income families. While low income families are often confused or put off by health service providers, the provider may be just as confused or put off by low income patients. It is helpful for

EPSDT workers to understand the sources of such annoyance and frustration in order to help providers and clients avoid potential problems.

For the most part, low income patients and health service providers come from very different backgrounds. If there is a language difference, the provider may not understand what the patient is saying and vice versa. Even if they speak the same language, the experiences, life situations, and lifestyle of the patient and provider may be greatly dissimilar, providing still another source of potential discomfort.

People working in the health professions have certain expectations which many patients, and especially low income patients, may not fulfill: they expect patients to keep appointments on time; they tend to maintain professional distance between themselves and their patients; they expect medications to be taken as prescribed and recommendations about health care to be followed. Further, they expect patients to be able to describe their symptoms and to raise questions when unclear about the provider's instructions or explanations.

When a health service provider, physician, dentist, nurse, etc., encounters a low income patient, there is a good chance that these expectations will not be met. Low income patients often seek service on a walk-in basis, expecting service without prior appointment. When they do make appointments, they may be late or may not show up at all. Often, they do not have the background to clearly describe symptoms. Their lifestyles and situation may be considered unsanitary or unhealthy by providers who are used to serving more affluent patients.

The combination of the providers' expectations about what constitutes a "good" patient, coupled with the likelihood that low income families will not meet some of these expectations, means that some providers are not eager to treat low income patients. In addition, some providers may be prejudiced against low income people, or against the ethnic minorities who comprise a disproportionate number of the low income population. If these feelings intrude into the provider's manner, the patient and family, already sensitive and anxious about unfamiliar health services, may be further put off and may feel that they are getting less than adequate care. If this has happened before a family is offered a chance to take part in EPSDT, the family may refuse to participate. If it happens after

an individual has begun the EPSDT program, broken appointments and resistance to the program can result.

The EPSDT worker must be sensitive to possible breakdowns in communications between patient and provider, and possible problems on both sides of the relationship. In this way the worker can spot developing problems and help both health care providers and low income families avoid situations which can undercut the effectiveness of the EPSDT program.

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SECTION II

HEALTH PRACTICES OF FAMILIES FROM VARIOUS CULTURAL BACKGROUNDS

Because modern medical services may be unfamiliar or uncomfortable to some low income families, they may use the services of indigenous nonprofessional medical practitioners. These health service providers are often an integral part of the client's community, and EPSDT workers should understand the role they can play for low income families.

A folk healer who has an intimate knowledge of the culture and orientation of the patient could be a helpful ally of a program like EPSDT by helping the outreach worker gain the confidence of the community. Where the definitions of health and illness differ between the health care provider and patient, an indigenous folk healer could be a valuable bridge between two cultures. This can be especially helpful when health care providers try to offer preventive care for a well person in the form of immunizations and early treatment of illness but are frustrated because the patient does not understand or refuses these services. Indigenous folk healers can explain the value of these services and can help make preventive services seem more reasonable to the patient. Gaining their cooperation, however, may be difficult as they may have a vested interest in resisting modern medicine. By respecting the role of folk healers and trying to work with them or at least recognize their place in the community, EPSDT workers may reduce some of this resistance. The following illustrations highlight the role of such providers in their communities.

HEALTH PRACTICES OF LOW INCOME MEXICAN-AMERICANS

First or second generation Mexican-Americans may approach white or "Anglo" health care institutions with suspicion. While many upper and middle class Mexican-Americans have abandoned folk medical practices in favor of professional medicine, newly arrived immigrants and the poor of the barrios may favor the folk system over "scientific medicine."

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The major folk practitioner in a Mexican-American community is the curandero (curandera in the case of a woman). A good curandero shows great warmth and concern for both the patient and the family, offering advice, giving treatment, but requesting no fee. If the treatment proves successful, the family is expected to offer payment, but if the treatment fails, nothing is expected, and, in fact, the curandero may refuse to treat a patient who cannot be cured or who has a low chance of recovery. The family's turning to the "Anglo" doctor or hospital may indicate that the patient brought in for "scientific medicine" is afraid of dying or has a serious disability (otherwise he or she could have been cured by the curandero).

Some of the diseases on which a curandero focuses are those recognized by the more scientific medical community. There are, however, other kinds of illnesses which fit into the folk system of belief and practice, and it is for these illnesses that the curandero is most likely to be consulted. These diseases take the form of hot and cold imbalance, dislocations of internal organs, illnesses of magical origin, and illnesses of emotional origin.

HEALTH PRACTICES OF LOW INCOME NATIVE AMERICANS

Until recently there has been a tendency to discourage and downgrade the Indian medicine man and herbalist. Yet, for many years, these folk practitioners were the major source of medical service available for native Americans. In recent years increased federal monies for Indian medical care and the expansion of medical facilities for Native Americans have led to remarkable improvements in Indian health. However, the effects of poverty, loss of status, high rates of alcoholism, and tuberculosis are still prevalent in Indian populations.

Cultural and communication barriers continue between health care workers and native Americans, but the most successful of these workers recognize the importance of the Indian medicine man, and try to cooperate with rather than oppose him. Cooperation with the medicine man and recognition of his role for his people has paved the way for Indians' acceptance of "scientific medicine." However, when an adversary relationship marks the boundary between the white man's and

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the Indian's medicine, complete acceptance of public health programs is a slow process. Today more and more indigenous health workers have helped the Indian develop a more favorable view of Western medicine, and clearly the success of disease treatment with the methods of "scientific medicine" has done much to allay the Indians' suspicions. Among the Navaho, for example, a factor in changing long-term suspicion into favorable support has been success in the treatment of tuberculosis. Until such a treatment was developed, all that Western medicine could offer was palliative therapy which was no more effective than that of the medicine man. In fact, the medicine man was seen as more beneficial because he treated infected persons at home instead of sending them off to the hospital to die. The lesson is clear: only when the people could see that a medical program was actually doing some good did they begin to believe in its merit. This suggests that a program like EPSDT must be seen as clearly beneficial in order to overcome client suspicion and resistance.

HEALTH PRACTICES OF LOW INCOME BLACK AMERICANS

Because of the difficulties in obtaining good medical care, many low income black people have tended to rely on folk medicine. The referral system for people seeking medical care in the black community begins when a person asks friends for advice and home remedies. This usually happens before the individual turns to a physician. The chief distributors of folk remedies in the black community are older women who have gained knowledge through long experience. Even when professional health care is sought, it is likely to be sought from black doctors. By keeping the search for medical care within the local community, poor black people reduce their fear of discrimination and their distrust of large impersonal "white" hospitals.

EPSDT workers should be aware of the effect that long years of discrimination have had on black people's perceptions of social and health service programs. Though their distrust may not be openly expressed, it may influence them to drop out or not participate, and only by building a personal relationship of trust with the client, can the EPSDT worker allay such suspicion.

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SECTION III

EPSDT OUTREACH AND FOLLOW-UP WITH LOW INCOME FAMILIES

Awareness of the life situation of EPSDT clients, their experience with health services, and their tendency to use nonprofessional as well as professional services can help EPSDT workers with outreach and follow-up tasks. The special needs of low income families make it especially important for them to understand the value of preventive health care and trust EPSDT workers and the program they represent.

There may be instances where an EPSDT worker will be frustrated and annoyed with a client who appears apathetic or repeatedly breaks appointments. By understanding some of the reasons behind such behavior, EPSDT workers will be in a better position to work with their clients and ensure full utilization of EPSDT services.

EPSDT workers do not face an easy job. They seek to modify long-standing patterns of health care utilization and should realize that there will be resistance. Building a close personal relationship with clients will help but it is not enough. The families taking part in EPSDT must realize and believe in the benefits of this program. They and the workers who serve them must struggle against the anxiety and unfamiliarity which often surround health care. By gradually shifting the emphasis from remedial to preventive care, the EPSDT worker can help parents of eligible children move toward fulfillment of the program goals of early detection and treatment of health problems.