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AUTHOR Wells, Nora
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ABSTRACT

This article discusses Medicaid's EPSDT (Early and Periodic Screening, Diagnosis and Treatment) program, which is a significant funding source for a wide variety of early intervention services for Medicaid eligible children. Strategies and questions that can help clarify and improve programs in each state are discussed, and important issues to consider as the nation grapples with health care reform are identified. Some of these include: (1) Medicaid eligibility; (2) requirements of Medicaid's EPSDT program; (3) benefits/reimbursable services under the program; (4) implications for early intervention programs; (5) potential problems; (6) strategies for advocating for fuller implementation of EPSDT; (7) questions for families and advocates to ask about EPSDT; and (8) health care reform. (SG)

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EARLY CHILDHOOD BULLETIN

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MEDICAID/EPSTDT FUNDING FOR
EARLY INTERVENTION

By

NORA WELLS

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EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils

Winter

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Medicaid/EPSTD Funding for Early Intervention

By Nora Wells, Resource Specialist

CAPP /National Parent Resource Center, Federation for Children with Special Needs

Funding is a crucial issue for early intervention services in every state and some jurisdictions. Presently, funding for these services often comes from a variety of sources. Medicaid, specifically through its EPSTD (Early and Periodic Screening, Diagnosis and Treatment) Program, is a significant funding source for a wide variety of early intervention services for Medicaid-eligible children. According to recent testimony by Allan Bergman, director of State-Federal Relations for United Cerebral Palsy Associations, before the House Subcommittee on Select Education and Civil Rights, "At least 40 percent of the infants and toddlers enrolled in Part H are Medicaid eligible and ... therefore eligible for ... its EPSTD program."

Yet this funding source is not well understood by families or providers and, therefore, is not being tapped to the extent possible. Furthermore, as our whole health care financing system gears up for reform, it is especially important that

parents and advocates working to ensure the continued availability and growth of early intervention services understand the possible implications of reform proposals for the EPSTD program.

ICC parent members who are aware of EPSTD and understand its potential for funding early intervention services can advocate for full implementation of this program in each state. The comprehensive services covered under EPSTD can also serve as a model for the scope and duration of services that should be available to *all* children with special needs as we participate in efforts to reform our health care system.

This article discusses Medicaid's EPSTD program as it currently exists, suggests strategies and questions that can help clarify and improve programs in each state, and identifies important issues to consider as our nation grapples with health care reform.

Each state has a Medicaid program jointly funded by federal and state dollars. The federal government, through the Health Care Financing Administration (HCFA), U.S. Department of Health and Human Services, requires each state to draw up a state plan for its Medicaid program describing who is eligible and what services are covered as benefits.

Every state must include a specified set of basic health services for all eligible clients, and may include a variety of optional health services (listed on page 2). Optional services become mandatory for Medicaid-eligible children through the EPSTD program if the service is identified as "medically necessary" to treat a condition uncovered during a child's "screening exam."

MEDICAID ELIGIBILITY

Given the variation and complexity of the ways to become eligible for Medicaid, often the family's or advocate's first problem is finding out whether or not the child is eligible for Medicaid in the first place. Early intervention (EI) programs, Medicaid programs, Parent Training and Information Centers (PTIs) and other parent groups in each state should be sources of state-specific

information about Medicaid eligibility. The state legal services program or disability advocacy groups are often knowledgeable about Medicaid programs, and may be able to help families who have been denied services or access to a program.

States designate who is eligible for Medicaid programs in their state according to federal guidelines. Children receiving public assistance through Aid to Families with Dependent Children (AFDC) are eligible for Medicaid, and other children may be eligible, based on their family income. Pregnant women and children up to age six whose family income falls below 133 percent of the federal poverty level,* as well as children born after September 30, 1983, with family income up to 100 percent of the federal poverty level, are now eligible for Medicaid. States have the option to include women and infants (up to age one) with incomes up to 185 percent of the federal poverty level. In some states, families with income or resources greater than those allowed by Medicaid may qualify for a "spend-down" program. Under a spend-down program, Medicaid pays for medical expenses

* The federal poverty line in 1993 was \$14,340 for a family of four.

within a specific time frame after a family has incurred a specific amount of medical expenses.

In most states,* children are eligible for Medicaid if they qualify for SSI (Supplemental Security Income). To be eligible for the SSI program, children must fit the SSI definition of disability and meet income guidelines. To qualify as "disabled," a child must have a documented special need that matches one of the categories of disability outlined by SSI, or have documented delays in "activities of daily living" (mobility, self-care, speech, etc.). The SSI definition of disability has recently been made more lenient by a Supreme Court ruling referred to as the *Zebley* decision. To meet the income guidelines for SSI eligibility, the family's income must fall below guidelines established by the federal government. These income guidelines are set higher for SSI than for most other programs that grant Medicaid eligibility. In these same states, if a child fits the SSI definition of disability and is in an institution (such as a hospital) for 30 consecutive days in a calendar month,** he or she becomes eligible for SSI Medicaid regardless of family income for the duration of the stay.

In some states, children considered at risk for institutionalization may be eligible for Medicaid without regard to their family's income through special home- and community-based waiver or amendment programs. Each state with a waiver or amendment defines the population of children to be served.

EPSDT

EPSDT is a required part of every state Medicaid program. It was designed "to discover, as early as possible the ills that handicap our children," and to provide "continuing follow up and treatment so that handicaps do not go neglected." It clearly intends to offer access to a wide range of health services to all Medicaid-eligible children under age 21. This program, however, is not well understood, and states have been slow in implementing it. As the country discusses health care reform, it is particularly important for families and advocates to understand the services EPSDT should be offering children so that these benefits will be preserved under any reforms.

Through EPSDT, all states are required to:

- Identify and inform all Medicaid-eligible children

* Exceptions: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Carolina, North Dakota, Ohio, Oklahoma and Virginia. Many children in these states would also be Medicaid eligible, although through a different process.

**Yes, the 30 days must all fall within the same month for the child to be considered eligible.

about the EPSDT program and help families find and use services;

- Provide all needed assessments of a Medicaid-eligible child's mental, physical and developmental health needs, including vision, hearing and dental; and
- Provide all necessary treatments for identified physical and mental needs in a timely manner, without limits on the "amount, duration, or scope" (the number of treatments by a doctor or therapist, for example) as long as services are reimbursable under Medicaid (even if they are not a part of the state plan).

The child is assessed through a screening that must include:

- a comprehensive health and developmental history,
- a comprehensive physical exam,
- appropriate immunizations,
- laboratory tests, and
- health education.

Screening schedules must meet reasonable standards of medical and dental practice, and children must be allowed a screen any time a physical or mental illness or condition is suspected. If a special need is found in any of the screening assessments, the child then is eligible for the expanded EPSDT benefits, which include *all optional benefits under Medicaid*, without limits on their "amount, duration or scope."

BENEFITS

The services reimbursable under all Medicaid plans include the following basic benefits in every state:

- inpatient hospital services,
- outpatient hospital services,
- rural health clinic services,
- other laboratory and x-ray services,
- nurse practitioner services,
- family planning services and supplies,
- physician services,
- nurse midwife services, and
- EPSDT.

For Medicaid-eligible children found to have a special health need, all the following Medicaid services, which are considered "optional" under other Medicaid programs, are mandated under EPSDT in every state:

- podiatrists' services;
- optometrists' services;
- chiropractors' services;
- psychologists' services;
- other practitioner services recognized by state law (such as nutritionists, dieticians, medical social workers, etc.);
- private duty nursing;

- inpatient psychiatric services;
- clinic services, skilled nursing services;
- dental services;
- emergency hospital services;
- personal care services;
- prescribed drugs;
- case management;
- hospice services;
- diagnostic services;
- preventive services;
- rehabilitative services;
- intermediate care facilities for the mentally retarded;
- Christian Science nurses/sanatoria;
- physical therapy;
- occupational therapy;
- speech/language/hearing services;
- prosthetic devices;
- eyeglasses;
- transportation;
- respiratory care services for children who are ventilator dependent.

Clearly, benefits that all states are required to provide to Medicaid-eligible children under EPSDT are extensive. Some states are very effective in assuring that their Medicaid-eligible children receive a wide range of these benefits. Items not listed separately may be covered by virtue of a state's interpretation of a listed item. For example, states include over-the-counter medication and supplies, such as diapers for older children, prescribed by a nurse or doctor.

IMPLICATIONS FOR EI PROGRAMS

The Medicare Catastrophic Coverage Act of 1988 amended Medicaid to make federal Medicaid matching funds available to schools and to early intervention programs for the cost of "related services" (including assistive technology devices and services) in a school-age child's IEP or an infant's or toddler's IFSP. Therefore, for Medicaid-eligible children, the entire range of EPSDT services (if included in an IFSP as medically necessary) could be supported with federal matching dollars. Some states, in fact, use the IFSP as valid documentation of medical necessity for Medicaid funding purposes. Because of this law, most state Medicaid agencies now allow school districts and early intervention providers to obtain reimbursement for such services, and many of them rely on these funds. However, most states are still in the early stages of implementing this program.

POTENTIAL PROBLEMS

Even if they know how extensive services should be, families may face problems obtaining them. As one

family commented, "Sometimes it is very hard to get clear and accurate information about how a family accesses EPSDT services, even from the Division of Medicaid."

- Families may not know what services are potentially available, such as transportation vouchers or tokens, and, therefore, may not request them.
- Some services – case management, for example – may be available only through an agency or provider that the family may not find helpful.
- To receive Medicaid funds, all providers must be approved by Medicaid. Sometimes there are not enough approved providers, or they may not be easily accessible to families.
- A state's Medicaid reimbursement rates may be low for some services, limiting the number of providers who seek Medicaid approval. With a limited number of providers, families may have to wait a long time for a Medicaid-approved assessment or service.
- Medicaid, by law, must be the payer of last resort. This means that the service must be billed first to any available private insurance the family has. Children may do without needed services, even when they are covered by *both* Medicaid and private insurance, while programs argue over who will pay for what. (However, if a child is also eligible for Part H, the state is required to use Part H funds or other funds to assure that services are provided while financial responsibility is being determined.)
- Services must be deemed "medically necessary," although the way this determination is made may not be clear to a family or provider. The Medicaid agency is not allowed to make the decision about "medical necessity" in an arbitrary or unreasonable manner. Recipients can appeal Medicaid decisions.
- Prior authorization may be required. Once again, the family and provider may not be aware of this need, or how the process works. Prior authorization cannot be required for periodic screens, and prior authorization requirements should not be used to limit or prevent access to needed medical services. Families may appeal a decision that denies approval of a service or treatment.

STRATEGIES

ICC parent members and other family members can play an important role in advocating for fuller implementation of EPSDT within their own state and in promoting EPSDT as a model of comprehensive benefits for all children. The following list suggests some advocacy strategies:

- Communicate to Medicaid and EPSDT staff workers

the questions and concerns of families about the programs.

- Ask your state Part H Coordinator about established linkages between Part H and EPSDT.
- Find out what information on the benefits, eligibility, application process, prior approval, etc., for all Medicaid programs is available for families. Early intervention programs, PTIs and advocates should keep these materials and sample applications on hand and actively disseminate information about state Medicaid programs to families.
- Identify the appropriate people for families to call with basic or specific questions about benefits, eligibility, and process.
- Identify knowledgeable individuals both in Medicaid programs and in other agencies and advocacy organizations to whom families can go for help.

QUESTIONS FOR FAMILIES AND ADVOCATES TO ASK ABOUT EPSDT

- How does a family apply? What documentation is needed to establish eligibility? Who is available to help a family gather the needed materials?
- What services require prior approval, and how is it obtained? What process is used to determine if a service is medically necessary? How are decisions made about the amount or kinds of services that will be covered?
- Is there a system for writing "care management plans" or for other case management? Who is responsible? Can this person be the Part H Service Coordinator? What role can the family play?
- How can Part H Service Coordinators help families access EPSDT services?
- What are the steps in an appeals process if a family disagrees with a decision on Medicaid services? How does a family begin this process? Who can help?
- What are the expected timelines for each step, such as acting on an application, determining eligibility, learning whether or not a benefit is approved, or responding to an appeal of a decision?
- Is there an avenue such as an advisory committee for family input to Medicaid programs and policies?

Medicaid funds are allocated by state legislatures as well as the federal Congress. Families should let both state and federal legislators know of problems they have in understanding or accessing Medicaid programs.

HEALTH CARE REFORM

Health care reform raises questions for families of children with special health needs, although the overall intent of some of the proposed reform measures is positive. The Clinton proposal (the Health Security Act) contains an entitlement to a basic health plan for all Americans, prohibits exclusions based on disability or pre-existing conditions, and has no lifetime caps. It would mandate community rating of insurance premiums so that everyone would pay the same "community" rate for basic health care coverage, regardless of need for health care. It also takes a significant step toward developing a national program for home and community based long-term care for people with disabilities and special health needs.

However, there is some question about the extent to which the broad array of benefits available to Medicaid-eligible children under EPSDT will be preserved under the proposed Clinton plan. As proposed, this level of benefits would be provided for Medicaid-eligible children through a federally funded program for "poverty level children with special needs." The budget, however, would be capped based on current usage. Bergman cites a HCFA report that "...in FY 1993, the year for which the Health Security Act caps the federal contribution, only 41% of all eligible children for EPSDT had been enrolled by the states."¹ The funds allocated, therefore, may not be sufficient to provide the appropriate level of services to all eligible children.

Advocates are working to ensure the future viability of this important source of funding for critical early intervention services, and to promote EPSDT as a model for the scope of services that should be available to all children with special needs who need them.

¹Bergman, Allan I. Testimony on the Impact of Health Care Reform on Individuals with Disabilities before the U.S. House of Representatives Committee on Education and Labor, Subcommittee on Select Education and Civil Rights. February 3, 1994. (This testimony contains a detailed analysis of the IDEA/Medicaid connection with state examples.)

Families of children with disabilities and special health needs have important perspectives that should be shared as our country debates health care reform. For more information, readers may contact Nora Wells or Janet Vohs at the Federation for Children with Special Needs, 95 Berkeley St., Boston, MA 02146; (617)482-2915.

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