The twenty-first century! How different things are today. Travel to Europe in the late 1960s often meant sending a telegram to family rather than making a long distance phone call. The alternative could have been waiting several hours at a Western Union office until an overseas line became available. For those of us who worked at offices in the late 1980s, it meant using typewriters and carbon paper, and a trip to the copier often resulted in ink-stained hands.

Technology has changed our daily lives in significant ways. When we travel, even in Europe, we can call home from almost any telephone and only worry about time zones. We can email a message half-way around the world in almost an instant. Do they still make typewriters?

For persons with disabilities, technological advancements have literally generated a life of opportunities unprecedented in any other generation. Power wheelchairs with sip-and-puff or head array mechanisms have permitted independent mobility to those who are unable to use joysticks. Augmentative communication devices have given those with speech obstacles the means of communication and expression.

As technology becomes more sophisticated, it also becomes increasingly expensive and identifying funding sources for assistive technology (AT) remains a constant challenge. The goal is well worth the effort, though, especially for children with disabilities.

Our lead article looks at Medicaid, one of the biggest funding sources of AT for children. After providing some background on Medicaid and how it funds AT, we will focus the discussion on Medicaid’s Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program. We will explain how EPSDT, a mandatory Medicaid program for children under 21, opens the door to all mandatory and optional categories of Medicaid coverage. We will also explain how the statutory, regulatory, and federal policy language supports an expanded view of what qualifies as medically necessary equipment for children. Finally, we will provide examples of special equipment that has been funded through EPSDT and the ways that courts
have interpreted the EPSDT mandate.

Overview of the Medicaid Program

Medicaid is a joint federal-state program, established under the Social Security Act. Medicaid is, in effect, an amalgamation of federal and state statutes, regulations and policy. Its complexity is legendary. Courts have called it “an aggravated assault on the English language, resistant to attempts to understand it,” Friedman v. Berger, 409 F.Supp. 1225-26 (D.C.N.Y. 1976), and “almost unintelligible to the uninitiated . . . doubly unfortunate in the case of a statute dealing with the rights of poor people.” Friedman v. Berger, 547 F.2d 724, 727, n. 7 (2d Cir. 1976), cert. denied, 430 U.S. 984 (1977).

A state need not participate in the Medicaid program, but if it does, it must comply with federal mandates. Participating states must provide a number of medical services, such as laboratory and x-ray services, nursing facility services, physician’s services, and inpatient hospital services. 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a)(1)-(5), 17, 21; 42 C.F.R. §§ 440.10-440.50, 440.70, 440.210, 440.165 and 440.166. States have the option of providing other services, including private duty nursing, physical therapy and related services, dental services, prescribed drugs, and prosthetic devices, to name a few. States are required to submit a State plan to the Centers for Medicare and Medicaid Services (CMS, the federal agency that oversees Medicaid), outlining the range of services it intends to provide. CMS approves the State plan if it believes the plan complies with federal Medicaid law.

In the federal Medicaid scheme, medical equipment and appliances are included in “home health services.” 42 C.F.R. § 440.70(b)(3). Known as “durable medical equipment” (DME) by most funding sources, including Medicaid, states are allowed some latitude in defining DME.

To complicate the matter, a particular piece of equipment may fit within more than one of Medicaid’s service categories. See, e.g., Charpentier v. Kizer, 1990 WL 252191 (E.D.Cal. 1990) (a wheelchair may fit under the prosthetic device and DME categories); Ohlson v. Weil, 953 P.2d 939 (Colo.App.1997) (without reaching a decision as to whether a body brace fits within the definition of either prosthetics or DME under state law, the court held that a single device may be covered under both categories); Fred C. v. Texas Health & Human Services Commission, 924 F.Supp. 788 (W.D.Tex.1996) (an augmentative communication device was covered both as DME and as a prosthetic device); William T. ex rel. Gigi T. v. Taylor, 465 F.Supp.2d 1267 (N.D.Ga. 2000) (augmentative communication devices meet the definition of DME, prosthetic devices, and speech-language pathology equipment, 42 C.F.R. § 440.110(c)); Meyers by Walden v. Reagan, 776 F.2d 241 (8th Cir.1985) (augmentative communication devices are included in the “physical therapy and related services” benefits category which includes speech services).

While home health services is not listed as a required category, a State plan for services must provide for the inclusion of home health services for any individual who, under the State plan, is entitled to nursing facility services. 42 U.S.C. § 1396a(a)(10)(D). Since nursing facility services is a mandatory category, some advocates believe this makes home health services a mandatory service as well. This was the position taken by CMS in a letter distributed to State Medicaid Directors, dated September 4, 1998, in which it noted, “[a]s you know, the mandatory home health services benefit under the Medicaid program includes coverage of medical supplies, equipment, and appliances suitable for use in the home (42 C.F.R. § 440.70(b)(3)).” [Available at www.cms.hhs.gov/smdl/downloads/ SMD090498.pdf.] In contrast, a number of courts have regarded “home health services” and therefore medical equipment, as an optional category. See Lankford v. Sherman, 451 F.3d 496, 511 (8th Cir. 2006).

Whether optional or mandatory, each service must be sufficient in amount, duration, and scope to reasonably achieve its purpose. Services may be limited by medical necessity, or by utilization control procedures, such as a prior approval process. 42 C.F.R. § 440.230. The definition of “medical necessity” may exclude experimental services or states may manage costs by requiring that the least costly medically effective alternative be provided.

Incredibly, courts are divided on whose purpose is to be achieved by the service. In Brisson v. Department of Social Welfare, 702 A.2d 405 (Vt.1997), the court held that services must be sufficient to achieve a federal purpose. Once Vermont chose to provide eyeglasses, it was bound to cover items that fall within the scope of the federal definition of eyeglasses, including a closed-circuit television (CCTV). In contrast, the court in Callen v. Rogers, 168 P.3d 907 (Ariz.App.Div 1, 2007), determining that services must be sufficient to achieve the state’s
purpose in covering an optional category, held that a state could limit dental services to those who had an emergency need for them.

The court in Lankford v. Sherman, supra, held that once a state provides an optional category, “failure to provide Medicaid coverage for non-experimental, medically-necessary services within a covered Medicaid category is both per se unreasonable and inconsistent with the stated goals of Medicaid.” 451 F.3d at 511. The court in Lankford was dealing with Missouri’s effort to limit coverage of DME by excluding most items, including wheelchair accessories, batteries and repairs, for all Medicaid recipients except those blind, under 21 or pregnant.

In Esteban v. Cook, 77 F.Supp 2d. 1256 (S.D.Fl. 1999), the court held that a $582 cap on wheelchairs was insufficient to reasonably achieve the state’s own purpose of providing wheelchairs to adults with severe mobility impairments. The court in Esteban cited the September 4, 1998 CMS policy letter mentioned above, which advised the State Medicaid Directors that while the state may maintain a list of pre-approved items of DME for administrative convenience, federal law required that a state have a policy that provides a reasonable opportunity for requesting items not on the list.

The EPSDT Program

The History of the EPSDT Program

In 1967, Congress amended the Medicaid Act to create a mandatory category of services for Medicaid recipients under the age of 21. 42 U.S.C. § 1396d(a)(4)(B), as amended, provided for “such early and periodic screening and diagnosis ... to ascertain...physical or mental defects, and such health care, treatment, and other measures to correct or ameliorate defects and chronic conditions discovered thereby . . . .” The impetus behind passage of the EPSDT program was recognition that poverty bears consequences for children that extend into adulthood, and that if childhood illnesses, defects and conditions are diagnosed and treated early, they are likely to be less complex and less costly to treat than if they were dealt with later as an adult. (Note: The word “defect” is used below to describe disability because that was the term used by Congress in the EPSDT provisions.)

In 1989, concerned by the number of states that were still not providing comprehensive health care services to children, Congress amended the Medicaid Act again, strengthening and expanding the mandates of EPSDT, and adding a requirement that states provide for “[s]uch other necessary health care, diagnostic services, treatment, and other measures described in section 1905(a) to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan.” 42 U.S.C. § 1396d( r)(5) (emphasis added).

According to the CMS State Medicaid Manual, Overview, § 5010(B), EPSDT services were intended to be a comprehensive child health program. As noted in Frew v. Gilbert, 109 F.Supp.2d 579, 662 (E.D. Tex. 2000), “[t]he plain language of the statute demonstrates that Congress was attempting to increase preventive healthcare services for minor Medicaid recipients.” The EPSDT program, then, is a comprehensive and preventive system of health care available to all Medicaid recipients under the age of 21. It imposes an obligation upon each State to offer a program that includes: outreach and informing; screening, diagnosis and treatment services; adequate provider participation; and reporting. 42 U.S.C. § 1396d(r); 42 C.F.R. §§ 441.50 et seq.

EPSDT Mandates Periodic and Comprehensive Health Assessments.

As a basic requirement of EPSDT, a child’s health needs must be assessed through initial and periodic (regularly scheduled) screening and evaluation. A screening must include, but not be limited to, a comprehensive health and developmental history, a comprehensive unclothed physical examination, appropriate vision testing, appropriate hearing testing, appropriate laboratory tests, and dental screening services. 42 C.F.R. § 441.56.

The comprehensive health and developmental history assessment must determine whether the individual’s developmental processes fall within a normal range of achievement according to age and cultural background. The CMS State Medicaid Manual, Part 5, § 5123.2(A)(1)(a), states that assessments should at least include the following elements:

- gross motor development, focusing on strength, balance, and locomotion;
- fine motor development, focusing on eye-hand coordination;
- communication skills or language development, focusing on expression, comprehension, and speech articulation;
- self-help and self-care skills;
- social-emotional development, focusing
on the ability to engage in social interaction with other children, adolescents, parents, and other adults;

• cognitive skills, focusing on problem solving or reasoning;

• as children age, visual-motor integration, visual-spatial organization, visual sequential memory, attention skills auditory processing skills, auditory sequential memory; and

• for adolescents, potential presence of learning disabilities, peer relations, psychological/psychiatric problems and vocational skills.

Once a defect, physical or mental illness, or condition has been identified by a screen, any service necessary to correct or ameliorate said defect, illness or condition must be provided to an EPSDT recipient whether the service or item is otherwise included in the State plan. 42 U.S.C. § 1396d(r)(5); 42 C.F.R. § 441.50; CMS State Medicaid Manual, Basic Overview §§ 5110, 5122. All the optional categories of service become mandatory for Medicaid recipients under the age of 21. (Note: The CMS State Medicaid Manual is available at www.cms.hhs.gov/Manuals. At time of press, the State Medicaid Manual was located under “Paper-Based Manuals.”)

**EPSDT Broadens the Definition of “Medical Necessity.”**

If every periodic screening is to assess for such developmental elements as social-emotional development, self-help and self-care skills, and the ability to engage in social interaction with peers, parents and other adults, and if EPSDT mandates treatment for any disabilities or medical conditions found through these assessments, then clearly the concept of “medical necessity” for Medicaid recipients under the age of 21 must include these developmental elements.

For example, in New York, a power wheelchair with sip-and-puff mechanism was requested for an eight year old who had suffered a severe spinal cord injury. The child could not use a traditional joystick and the sip-and-puff mechanism was required for independent mobility. The administrative fair hearing decision noted important reasons why the requested wheelchair was medially necessary for the child: to maximize his opportunity for physical and cognitive development; to allow him to become more responsible for his own self care and safety in a home environment; and to foster his learning capacity and general ability to explore his environment, “as is necessary for any child” of his age. Matter of J.P., FH # 3689971R (copies available through the AT Advocacy Project). Although the request was not evaluated under EPSDT, the decision nonetheless recognized developmental elements as components of medical necessity for the child in question.

Several courts have used Webster’s Dictionary to determine the parameters of “ameliorate,” noting it means “to make better or more tolerable.” See Ekloff v. Rodgers, 443 F.Supp.2d 1173 (Ariz. 2006) (noting a strong inference in the Congressional Record that EPSDT was intended to be inclusive rather than exclusive, and preventive treatments are required under the phrase “to correct or ameliorate”); Collins v. Hamilton, 231 F.Supp.2d 840 (S.D. Ind. 2002) (treatment required if it makes a condition more tolerable).

In C.F. v. Department of Children and Families, 934 S.2d 1 (Fla.App. 3 Dist. 2005), the court, noting that the Medicaid agency failed to incorporate EPSDT requirements into the definition of “medical necessity,” held that the federal law required the state to provide services that support and sustain, rather than actually treat the disability. Addressing medical necessity in the context of the plaintiff’s need for personal care services, the court reasoned: “The state definition of medical necessity is a narrower view that does not encompass the assistance a caretaker would need in taking care of a disabled child. The federal definition, on the other hand, encompasses a more expansive view, allowing for services that sustain or support, as opposed to actually treating the disability.” 934 S.2d 5.

In S.D. ex rel. Dickson v. Hood, 391 F.3d 581 (5th Cir. 2004), plaintiff’s physician prescribed disposable incontinence underwear as health care necessary to ameliorate the plaintiff’s mental and physical conditions. Incontinence underwear was needed to draw moisture away from the skin and therefore prevent chronic irritation and infection caused by urine. Further, without these supplies, the plaintiff would be “home bound, isolated, and unable to attend school or engage in other age-appropriate activities.” 391 F.3d at 585. The state claimed incontinence supplies were not covered under the State plan approved by CMS. In ruling that Louisiana’s Medicaid agency unlawfully denied the plaintiff’s claim for EPSDT services by refusing to pay for disposable incontinence underwear, the court noted its agreement with federal appeals courts from other circuits which held that Congress did not grant or allow states dis-
crent to define the types of services that would be provided EPSDT recipients. 391 F.3d at 593 (citing cases from the Seventh, Eighth, and Eleventh Circuits). (We recommend reading the S.D. v. Hood decision, as it provides a good analysis of why children are entitled to all potential services through EPSDT.)

In New York, Medicaid denied prior approval for a power wheelchair for a four year old child unable to self-propel a manual wheelchair, claiming, among other things, that the child needed constant supervision and therefore, always had a care giver available to push a manual wheelchair. A fair hearing was held, at which the child’s current and prior physical therapists testified that the child’s continued reliance on care givers would be developmentally inappropriate. Although the hearing decision never specifically cited EPSDT, this testimony was mentioned in support of its direction that the agency approve the power wheelchair. Matter of John, FH # 4337314K (copies available through the AT Advocacy Project).

An interesting case from Georgia, Department of Community Health v. Freels, 576 S.E.2d 2 (2002), highlights how expansively EPSDT can be applied. The case involved a request for hyperbaric oxygen therapy (HBOT) for a child diagnosed with cerebral palsy. HBOT is a process of enclosing a patient’s body in a pressurized vessel containing pure oxygen, which causes an increase in the amount of oxygen dissolved in the patient’s blood. The child’s physician was board-certified in the field of hyperbaric medicine and he claimed extensive experience in using a technique known as a SPECT (single photon emission computed tomography) scan, which is a functional image of the blood flow in the brain. The physician scanned the child both before and after administering several HBOT treatments and reported a significant improvement in the flow of oxygen in the brain, particularly in the speech motor area.

The Medicaid agency denied the request for HBOT, claiming that it had not been proven to be medically necessary for the child, was experimental/investigational in the treatment of cerebral palsy, and was not a generally medically accepted practice at that time. The Georgia definition of “medical necessity” provides for services which “are reasonable and necessary in establishing a diagnosis and providing palliative, curative or restorative treatment for physical and/or mental health conditions.” It further provides that medical necessity will be determined in accordance with currently accepted standards of medical practice.

In comparing the criteria of “medical necessity” with the mandates of EPSDT, the court noted that even if “palliative, curative and restorative treatment” are functionally equivalent to services which “correct or ameliorate” (as used in the Medicaid Act), federal law clearly did not require that a treatment be an “acceptable standard of medical practice” under EPSDT. 576 S.E.2d at 6. In effect, the Georgia appellate court agreed with the lower court’s reasoning that “[i]nstead of requiring proof that HBOT is the accepted standard medical practice, or that it meets the definition of medical necessity reserved for adult Medicaid recipients, the [Department] should have focused its inquiry on whether HBOT was necessary to correct or ameliorate [Freels’] physical condition.” 576 S.E.2d at 6.

The plaintiffs in Jackson v. Millstone, 801 A.2d 1034 (Md. 2002) challenged a Maryland regulation that required a provider seeking preauthorization to demonstrate that a particular Medicaid service was both “necessary” and “appropriate.” To be appropriate, a service would be considered in light of the particular circumstances of the individual and the relative cost of alternatives which could be used for the same purpose. Both plaintiffs were Medicaid recipients under the age of 21 who required life-saving liver transplants. The agency denied preauthorization for one child based on two prior failed transplants, and for the other child because the agency considered a transplant to be experimental in light of the child’s other health conditions. The court held that federal law only required a showing of medical necessity and applying an “appropriateness” criteria exceeded the dictates of federal law under EPSDT.

**EPSDT Mandates a Broad Range of Services or Treatments for Children Not Covered Under the Category of “Home Health Care Services.”**

The Medicaid Act requires states to provide diagnostic services, treatment, and other measures to correct or ameliorate conditions discovered by mandated screening, even when those services are not included in the State plan. 42 U.S.C. § 1396d(r). Optional categories become mandatory categories for Medicaid recipients under the age of 21. A wide variety of items or devices that are not covered as DME under the category of “home health services” for adults, are covered under EPSDT when such items or devices are medically necessary for persons un-
under age 21. Some of the categories that might include AT are:

- home health care services;
- physical therapy, occupational therapy, and speech-language pathology services (all include necessary equipment pursuant to 42 C.F.R. § 440.110);
- prescribed drugs, dentures, and prosthetic devices;
- eyeglasses prescribed by a physician skilled in diseases of the eye or by an optometrist, whichever the individual may select;
- other diagnostic, screening, preventive, and rehabilitative services, including any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.

42 U.S.C. § 1396d(a)(7), (11), (12), (13); see also 42 C.F.R. Part 440. [Please note: Some of the items discussed below, as available under EPSDT for children should also be available for adults. The fact that an item has been held to be available under EPSDT should not necessarily preclude its availability under traditional Medicaid criteria for adults.]

In S.D. ex rel. Dickson v. Hood, supra, the court held that incontinence supplies fall within the category of “home health services” and are therefore a form of medical assistance that must be covered under EPSDT, even if not covered for the general adult Medicaid community. “Thus the plain words of the statute and the legislative history make evident that Congress intended that the health care, services, treatment and other measures that must be provided under the EPSDT program be determined by reference to federal law, not state preferences. The 1989 amendment was clearly a response to the disappointing performance of the EPSDT treatment function as optional and within each state’s discretion.” 391 F.3d at 592.

The Health Care Financing Administration (HCFA, renamed the Centers for Medicare and Medicaid Services, or CMS) issued two policy letters, one dated March 7, 1996, and the other called “State Agency Letter Number 93-25,” in which it explained that medically necessary computers and computer software, exercise equipment (including exercise bikes, swing sets, and tricycles), communication devices such as the Dynavox, and an Apple II Computer with printers and various adapted software are covered by Medicaid under EPSDT if medically necessary. In these letters, HCFA declared that while states have wide latitude in how they decide to provide services, devices that fall directly under a category of services provided by Medicaid and determined to be medically necessary, must be provided to Medicaid recipients under the age of 21 pursuant to the mandates of the EPSDT. (Copies of these HCFA letters are available through the AT Advocacy Project.)

In a New York fair hearing, the issue was whether a medically necessary therapeutic tricycle for a 12 year old was covered by Medicaid. The agency argued that tricycles are exercise equipment that are useful in the absence of an illness or injury and denied prior approval. Medical documentation overwhelmingly proved that the child would medically benefit from a therapeutic tricycle but that she could not use one commercially sold “off-the-shelf.” The administrative law judge (ALJ) found in favor of the appellant child, without reference to the EPSDT provisions. The agency requested a corrected decision, claiming that the ALJ had erred as a matter of law and fact because tricycles are exercise equipment and Medicaid does not cover exercise equipment. Citing the March 7, 1996 CMS policy letter that specifically mentioned therapeutic tricycles as coverable for Medicaid recipients under the age of 21 if medically necessary, the principal ALJ denied the request, observing that “[c]onsiderable weight

Fair Hearing Decision Awards Special Wheelchair Features and Environmental Control Unit to Adult

After an administrative fair hearing, the agency was directed to approve wheelchair accessories, including a seat elevator, attendant controls and an environmental control unit for an adult Medicaid recipient. The environmental control unit was approved based on evidence that it was a feature needed for the appellant’s independence and safety, in that it would allow him to adjust heat, lights, or computer and would permit him access to a telephone in the event of an emergency. (Matter of Fred, FH # 4790256Q is available on request).
must be given to this broad interpretation of Medicaid policy by the federal agency.” Matter of Kaitlyn, FH # 4034949N (copies available from AT Advocacy Project).

Enforcement of EPSDT in the State and Federal Courts

The EPSDT program is an incredibly powerful vehicle for securing medical services for Medicaid recipients under the age of 21, but only if there are effective enforcement mechanisms available. Various provisions of the Medicaid Act, including EPSDT, have been enforced in the state and federal courts. Without commenting on any specific state court systems or limitations on jurisdiction, as a general rule the courts of your state will have jurisdiction to enforce violations of both state and federal Medicaid laws and regulations. In fact, as this is written all 50 states have judicial review statutes, allowing for court review of a final Medicaid fair hearing decision that is adverse to the Medicaid beneficiary.

Many attorneys prefer federal court as the place to enforce Medicaid rights. Since the Medicaid Act does not create its own federal cause of action, enforcement against State officials has historically been pursued through 42 U.S.C. § 1983. However, as many readers know, the ability to use section 1983 to enforce Medicaid Act provisions has been made more difficult in recent years. Any attorney who is considering the federal courts to enforce the EPSDT mandates would be wise to first contact our colleagues at the National Health Law Program before moving forward with your case (see box, this page).

A discussion of what the U.S. Supreme Court and the many lower courts have said about section 1983 and Medicaid Act enforcement is well beyond the scope of this short article. To provide some context for the problem with using section 1983 to enforce Medicaid Act provisions has been made more difficult in recent years. Any attorney who is considering the federal courts to enforce the EPSDT mandates would be wise to first contact our colleagues at the National Health Law Program before moving forward with your case (see box, this page).

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The message from Lankford and similar holdings to potential federal litigants is to carefully think through whether your case should be filed in the state or federal courts. If you do file your case in the federal courts, make sure you are up-to-date on what the courts in your Circuit have said about using section 1983 to enforce specific provisions of the Medicaid Act. And finally, do not overlook the possibility of using the Constitution’s Supremacy Clause as an alternative cause of action to challenge state laws that are inconsistent with federal mandates.

Conclusion

EPSDT is a comprehensive and preventive health care program that expands the definition of medical necessity and encompasses all available Medicaid services, even when those services are not included in particular States’ plans. As advocates share success stories, the application of EPSDT expands even further. Advocates are invited to send us their administrative fair hearing and court decisions. Please send decisions and other relevant matter to Jim Sheldon or Diana Straube, at jsheldon@nls.org or dstraube@nls.org.
The AT Advocacy Project will provide nationwide services to PAAT projects including technical assistance to advocates wanting to access funding for assistive technology for individuals with disabilities.

Update on The National Assistive Technology Resource Library

We have designed a word-searchable digest, using computer technology, to store and retrieve hearing decisions and other administrative documents. We also have indexed nearly 700 documents from more than 125 pending and decided court cases. All documents are available through our AT Resource Library. Please send us your hearing decisions, briefs and other documents involving AT.

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