#### HELPING THE MUTE TO SPEAK: THE AVAILABILITY OF AUGMENTATIVE COMMUNICATION DEVICES UNDER MEDICAID

#### ELLEN M. SAIDEMAN\*

Introduction		741
I.	The Need for Speech	743
II.	Communication Devices	744
III.	The Medicaid Statute	746
IV.	The Standard for Providing Augmentative Communication	
	Devices	<b>74</b> 9
V.	The Treating Professional Standard	751
Conclusion		753

#### INTRODUCTION

One of the most severe disabilities is the inability to speak. Nearly one-half million people in the United States with normal intelligence are unable to communicate either verbally or with standard hand signs. Perhaps 100,000 more have been diagnosed as retarded just because they do not have the physical ability to communicate. There are augmentative communication devices on the market today that would enable many people with severe speech impairments to communicate verbally. With the ability to communicate, many would be able to live independently and to be employed in positions commensurate with their abilities rather than their disabilities. Although our science and technology have created these devices, they are often unavailable to those

<sup>\*</sup> Staff Attorney, New York Lawyers for the Public Interest, Inc. B.A., 1979, Barnard College; J.D., 1982, Columbia University. I thank Peter Margulies and Herbert Semmel for their comments on prior drafts of this Article. I also thank Lew Golinker and Carol Schaeffler for their assistance in my work on augmentative communication devices. An earlier version of this material was presented at a colloquium entitled "Rights of People with Disabilities" sponsored by the N.Y.U. Review of Law & Social Change in April 1989.

<sup>1.</sup> Dahmke, Let There Be Talking People Too, BYTE, Sept. 1982, at 6; see also M. BAT-SHAW & Y. PERRET, CHILDREN WITH HANDICAPS: A MEDICAL PRIMER 239, 245 (2d ed. 1986) (individuals with extrapyramidal cerebral palsy often have severe dysarthria, a severe speech impairment caused by poor muscle control); Ford, Communicating with the Aphasic Patient, J. PRACTICAL NURSING, Apr. 1978, at 20 (individuals who have diseases of the central nervous system, cerebral vascular accidents, or strokes may suffer from aphasia, a language disorder characterized by impaired motor response and/or slowed comprehension).

<sup>2.</sup> Dahmke, supra note 1, at 6.

<sup>3.</sup> Griffin & Gerber, Non-Verbal Communication Alternatives for Handicapped Individuals, J. REHABILITATION, Oct.-Dec. 1980, at 36 ("Without the provision for the expression of language through alternate means, most non-verbal handicapped individuals may be consigned to a life of dependence and frustration.").

who need them most. Because the majority of people with severe disabilities are unemployed and dependent on government benefits,<sup>4</sup> access to this modern technology depends on government benefit programs.

This Article will focus on the availability of augmentative communication devices under Medicaid, which provides medical assistance to poor people, and will address the proper standard for providing augmentative speech devices through the Medicaid program.<sup>5</sup> There are some devices which are not programmable and only provide very minimal speech, enabling the user to communicate only the most basic information.<sup>6</sup> There are also other, more expensive devices that provide the user with access to unlimited vocabulary. The question then becomes whether a limitation of funding to a device that provides access to a limited number of words and phrases satisfies Medicaid's provision requiring that it give funds for "medical necessities." This Article concludes that federal and state laws and regulations provide that the appropriate test of medical necessity is whether the device corrects the speech im-

<sup>4.</sup> A 1985 Harris poll found that 70% of working age people with disabilities were unemployed. Shapiro, *Liberation Day for the Disabled*, U.S. News & World Rep., Sept. 18, 1989, at 22. The United States spends nearly \$60 billion each year on disability benefits and welfare costs for people with disabilities. *Id*.

<sup>5.</sup> Technological devices may also be available for adults through state vocational rehabilitation programs, and for children through special education programs. The Vocational Rehabilitation Act provides that benefits such as technological aids and devices will be provided. 29 U.S.C. § 723(a)(11) (1988). In most cases, however, vocational rehabilitation assistance is not provided unless there has been a determination that "comparable services and benefits are not available under any other program, except that such determinations shall not be required where it would delay the provision of such services to any individual at extreme medical risk." *Id.* § 721(a)(8). This provision does not apply to technological aids and devices. *Id.* § 723(a)(11).

The Education of the Handicapped Act [hereinafter EHA] provides children with disabilities with special education and related services. 20 U.S.C. §§ 1401(17), 1414 (1988). Speech pathology is explicitly included in the definition of related services. *Id.* § 1401(17). Medicaid cannot deny payment because of the availability of medical services and equipment under the EHA. The Medicaid statute provides that Medicaid will be a primary payor for medical/health services which are provided at school. 42 U.S.C. § 1396b (1988).

<sup>6.</sup> For example, the Vocaid device is a nonprogrammable augmentative communication device employing four panels which must be changed manually to fully implement its functional capacity. The Vocaid's manufacturer, Texas Instruments, has described the device as "particularly well-suited for persons with short-term speech loss, such as tracheotomy, laryngectomy or stroke patients." Texas Instruments, Vocaid Electronic Vocal Aid (1982). One panel is designed for emergencies and telephone conversations. In addition to the phrases "help! fire"; "help! medical"; "help! police"; and the numbers zero through nine, the panel has 22 other words and phrases: hello; voice message; please ask so I can answer; yes; no; goodbye; just a minute; my number is; wrong number; who is this?; please call back; how?; please spell it; I'll take a message; when?; I don't know; please explain; where?; maybe; why?; please repeat; and ignore last remark.

A second panel refers to activities of daily living geared to the person who is bedridden by illness (the "ADL" panel). It contains the following 35 words and phrases to be used separately or in combination: I would like to; have medical help; have my medicine; please hurry; use the bathroom; have it open; sit up; lie down; move; have more; sshl quiet; be left alone; have it on; read; write; bathe; have clean linens; I am; in pain; nauseous; hot; cold; dizzy; upset; hungry; thirsty; not; fine; tired; please explain; bored; ready; thank you; word help message; and ignore last remark. The third Vocaid panel contains the letters A to Z and the numbers one through nine; and the fourth panel relates to playing games.

pairment. Thus, a Medicaid recipient is entitled to a device which provides the user with unlimited speech.

### I. THE NEED FOR SPEECH

Language is the principal skill that distinguishes human beings from other animals.<sup>7</sup> Although human beings also communicate through gestures, facial expressions, and body language, language is our principal means of expression.<sup>8</sup> There are two principal types of language skills: receptive language and expressive language. Receptive language describes an individual's understanding of language, while expressive language describes the individual's ability to speak. Generally, expressive language evolves simultaneously with receptive language. By two years of age, a child usually has learned how to communicate through speech.<sup>9</sup> People who are severely speech impaired may have highly developed receptive language skills so that they understand what people tell them, but, without assistance, they are unable to express themselves through language, either orally or by hand.

The difficulties facing individuals with speech impairments are graphically described by Ruth Sienkiewicz-Mercer in her recent autobiography, I Raise My Eyes to Say Yes. 10 As a result of cerebral palsy, Ms. Sienkiewicz-Mercer is severely speech impaired and relies on a wheelchair for mobility. She lived in a state institution for the mentally retarded for more than sixteen years after she was diagnosed as an imbecile. She describes the doctor's evaluation: "His method of evaluating me consisted of looking me over during the physical exam and deciding that since I didn't talk and apparently couldn't understand what he was saying, I must be an imbecile."11 Although her other disabilities are severe, it is the lack of speech that troubles her the most. She writes, "Without a doubt, my inability to speak has been the single most devastating aspect of my handicap. If I were granted one wish and one wish only, I would not hestitate for an instant to request that I be able to talk, if only for one day, or even one hour."12 The basic problem that Ms. Sienkiewicz-Mercer has encountered throughout her entire life is that "when you can't talk, and people believe that your mind is as handicapped as your body, it's awfully difficult to change their opinion."13

The inability to speak can create medical problems. Ms. Sienkiewicz-Mercer provides an example. In April 1967, she was accidentally injured by

<sup>7.</sup> M. BATSHAW & V. PERRET, supra note 1, at 239.

<sup>8.</sup> *Id*.

<sup>9.</sup> Id. at 240.

<sup>10.</sup> R. Sienkiewicz-Mercer & S. Kaplan, I Raise My Eyes to Say Yes (1989) [hereinafter I Raise My Eyes].

<sup>11.</sup> Id. at 38.

<sup>12.</sup> Id. at 12-13.

<sup>13.</sup> Id. at 121.

an attendant.<sup>14</sup> For hours she was untreated because the attendants did not understand that she was in pain.<sup>15</sup> She was eventually treated for a broken leg, but she was unable to communicate to her doctors and nurses that she felt a pain in her left hip:

I tried to tell the doctors and nurses about it, but I couldn't communicate with them. Nobody had told them about my facial signals. The nurses didn't know if I was deaf, dumb, or what. The nicer ones spoke to me slowly and loudly, as if this would make it easier for me to understand them. I wanted to tell them that English was my native language and I understood them very well, but I couldn't get that message across. The nurses kept telling each other "I guess that she doesn't understand us" while I was flashing my yes expression so hard that my face hurt. 16

Her hip problem was not discovered by medical professionals until October 1969, more than two years later.<sup>17</sup> Had she been able to communicate her physical condition, she would not have had to endure years of unnecessary pain.

In addition to improving physical health, communication devices may improve mental health. Communication devices, for example, enable non-vocal individuals with multiple disabilities to receive psychotherapy and other mental health services. Individuals with speech impairments may seek assistance for a full range of psychological problems, including family difficulties and sexual issues. Without electronic communication devices, psychotherapy is practically impossible. Moreover, mental health services may further the rehabilitation of individuals with severe speech impairments. For example, a patient may be reluctant to use an electronic communication device because she feels it will emphasize her disability. With therapy, the patient may choose to use such a device. 22

## II. Communication Devices

Communication boards are widely used communication devices.<sup>23</sup> A

<sup>14.</sup> Id. at 128-29.

<sup>15.</sup> Id. at 130.

<sup>16.</sup> Id. at 132.

<sup>17.</sup> Id. at 145. Even after the hip problem was discovered, it was not properly treated by the doctor at Belchertown's infirmary. Her hip eventually improved with better padding for the wheelchair and better care. Id. at 146-47.

<sup>18.</sup> Crawford, Individual Psychotherapy with the Nonvocal Patient: A Unique Application of Communication Devices, 32 REHABILITATION PSYCHOLOGY 93 (1987).

<sup>19.</sup> Id. at 95.

<sup>20.</sup> Id.

<sup>21.</sup> Id.

<sup>22.</sup> Id.

<sup>23.</sup> Communication boards range from lap boards and notebook binders to messages on a piece of cloth that can be folded. The format of the board depends on the user's motor control,

communication board may provide pictures of items such as food, drink, or clothing and words. Depending on the user's other physical disabilities, the user may either point to the item or word that she would like to use, or may direct her communication to the item or word by gestures or facial expressions.

It is obviously difficult to carry on a conversation using such a device. First, the vocabulary and concept choices provided by the communication boards are limited.<sup>24</sup> In order to have a vocabulary of any size, the board must be extremely bulky and cumbersome.<sup>25</sup> Second, although spelling systems provide access to greater vocabulary, they make communication very slow.<sup>26</sup> Third, the communication board imposes great demands on the listener and often relegates the user to a passive role. It is easier to rely on "yes" or "no" questions than to engage in conversation. Furthermore, the user may find it difficult to initiate or direct conversation. Fourth, the board takes much more time than speech to express a message, affecting both the quality and quantity of the interaction.<sup>27</sup> Fifth, communication boards may limit conversations to those who can read or spell.<sup>28</sup> Sixth, one cannot use a communication board to converse over the telephone.

Computerized communication devices produce synthesized speech. Computerized devices can be programmed for the particular needs and interests of the individual user, and frequently can be adjusted. Because the devices produce oral speech, users can more easily communicate with others. With oral speech, users can communicate with people who cannot read. Computerized devices can also be used to communicate over the telephone. Such devices use a picture-oriented system so that individuals who cannot read or spell are able to use them.

To illustrate how a computerized device works, I will explain how one

manual dexterity, visual abilities, mode of mobility, method of message indication, type and number of messages, and the frequency of use. Mast, Selecting and Implementing Augmentative Communication Methods for Children, in Nursing and the Management of Pediatric Communication Disorders 226-27 (S. Shanks ed. 1983).

<sup>24.</sup> Beukelman & Yorkston, A Communication System for the Severely Dysarthric Speaker with an Intact Language System, 42 J. Speech & Hearing Disorders 265, 265 (1977).

<sup>25.</sup> For example, Ms. Sienkiewicz-Mercer has used boards with five sides containing over 1800 words and phrases. I RAISE MY EYES, supra note 10, at 155. Since 1986, she has also used electronic communication devices. *Id.* at 156.

<sup>26.</sup> Beukelman & Yorkston, supra note 24, at 265. Spelling systems are not useful for individuals who are illiterate or are poor spellers. In addition, spelling is very difficult for the listener, who must retain the sequence of letters. See, e.g., id. at 266, 268 (dysarthric individual had spelling rate of four words per minute).

<sup>27.</sup> Russel, Assessment and Intervention Issues with the Nonspeaking Child, 51 EXCEPTIONAL CHILDREN 64, 66 (1984).

<sup>28.</sup> Mast, supra note 23, at 227. Because many people with severe speech impairments did not receive appropriate education until recently, many are illiterate. Furthermore, potential communication partners, such as home attendants and family members, may be illiterate. Thus, communication boards may not enable users to communicate with their peers or with their family.

device, the Touch Talker or Light Talker,<sup>29</sup> works. The device has a picture board that utilizes as many as 128 squares that may be used for storing messages. Each square has a picture or symbol representing a word or phrase, which can then be used singly or in combination with other picture squares. The Touch Talker's keyboard can be operated by fingers, a mouthstick, or a head pointer. People who do not have the ability to touch but can make a body movement such as a brow wrinkle or the raising of a finger or knee can use a light sensor to activate the keyboard of the Light Talker.

### III. THE MEDICAID STATUTE

Augmentative communication devices come within the general purpose of the Medicaid statute. The Medicaid statute specifically states its purpose: to enable each state "to furnish (1) medical assistance on behalf of . . . disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services, and (2) rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care."<sup>30</sup>

It is clear, however, that federal law does not require all states participating in the Medicaid program to provide such devices. Congress has set a basic minimum standard for any Medicaid program. Congress requires participating states to provide financial assistance for certain specified medical treatment,<sup>31</sup> such as inpatient hospital services,<sup>32</sup> outpatient hospital services,<sup>33</sup> laboratory and X-ray services,<sup>34</sup> and nurse-midwife services.<sup>35</sup> Speech therapy and augmentative communication devices are not included in the mandatory Medicaid provisions.<sup>36</sup> Therefore, states may choose not to provide any speech services under their individual Medicaid programs.

States may, however, elect to provide any of the optional medical services listed in Title XIX of the Social Security Act.<sup>37</sup> Optional services include home health care,<sup>38</sup> private duty nursing,<sup>39</sup> dental services,<sup>40</sup> and physical therapy.<sup>41</sup> Speech therapy and augmentative communication devices fall within several of the optional services listed in Title XIX. The Medicaid stat-

<sup>29.</sup> This device is manufactured by the Prentke Romich Company.

<sup>30. 42</sup> U.S.C. § 1396 (1988).

<sup>31.</sup> Id. § 1396a(a)(10)(A).

<sup>32.</sup> Id. § 1396d(a)(1). Inpatient hospital services in an institution for mental diseases are not included in the mandatory hospital services. Id.

<sup>33.</sup> Id. § 1396d(a)(2).

<sup>34.</sup> Id. § 1396d(a)(3).

<sup>35.</sup> Id. § 1396d(a)(17). The statute covers only services that state law authorizes a nurse midwife to perform. Id.

<sup>36.</sup> See id. §§ 1396d(a)(1)-(5), (17).

<sup>37.</sup> See id. §§ 1396d(a)(6)-(16), (18).

<sup>38.</sup> Id. § 1396d(a)(7).

<sup>39.</sup> Id. § 1396d(a)(8).

<sup>40.</sup> Id. § 1396d(a)(10).

<sup>41.</sup> Id. § 1396d(a)(11).

ute specifically includes "physical therapy and related services" among the optional services, <sup>42</sup> and the federal regulations define "related services" to include services for individuals with speech, hearing, and language disorders. <sup>43</sup>

Thirty-three states provide Medicaid coverage for speech, hearing, and language disorders.<sup>44</sup> The federal regulation describes the speech therapy services covered by the Medicaid statute as "diagnostic, screening, preventive or corrective services provided by or under the direction of a speech pathologist or audiologist, for which a patient is referred by a physician. It includes any necessary supplies and equipment."<sup>45</sup>

An augmentative communication device which provides speech impaired individuals with the ability to communicate verbally is also a preventive or corrective service within the plain meaning of this provision. The Medicaid regulations describe preventive services as including those services provided to "promote physical and mental health and efficiency."

An augmentative communication device may also be considered a prosthetic device, a service which the Medicaid statute lists as among its optional services.<sup>47</sup> The federal regulation defines prosthetic devices as replacement, corrective, or supportive devices prescribed to prevent or correct physical deformity or malfunction.<sup>48</sup> An augmentative communication device replaces or corrects a speech impairment, which can be considered a physical deformity. Forty-seven states cover prosthetic devices.<sup>49</sup>

The Medicaid statute also includes "other diagnostic, screening, preventive and rehabilitative services." An augmentative communication device may be considered a rehabilitative service.<sup>51</sup> Thirty-nine states cover rehabili-

<sup>42.</sup> Id.

<sup>43. 42</sup> C.F.R. § 440.110(c)(1) (1990).

<sup>44.</sup> Alaska, Arizona, Arkansas, California, Connecticut, Florida, Hawaii, Illinois, Indiana, Iowa, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New York, North Dakota, Ohio, Oregon, South Dakota, Utah, Vermont, Virginia, Washington, West Virginia, and Wisconsin. 3 Medicare & Medicaid Guide (CCH) ¶ 15,504 at 6504 (Oct. 1989). The District of Columbia also covers speech, hearing and language disorders. *Id.* The seventeen states that do not specifically cover speech, hearing and language disorders are: Alabama, Colorado, Delaware, Georgia, Idaho, Louisiana, Mississippi, Missouri, New Mexico, North Carolina, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, and Wyoming. *Id.* 

<sup>45. 42</sup> C.F.R. § 440.110(c)(1) (1990).

<sup>46.</sup> Id. § 440.130(c)(3).

<sup>47. 42</sup> U.S.C. § 1396d(a)(12) (1988).

<sup>48. 42</sup> C.F.R. § 440.120(c)(2) (1990).

<sup>49.</sup> Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Georgia, Florida, Hawaii, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Utah, Vermont, Washington, West Virginia, Wisconsin, and Wyoming. 3 Medicare & Medicaid Guide (CCH) § 15,504 at 6504 (Oct. 1989). The District of Columbia also covers prosthetic devices. Prosthetic devices are not covered by three states: Idaho, North Carolina, and Virginia. Id.

<sup>50. 42</sup> U.S.C. § 1396d(a)(13) (1988).

<sup>51. 42</sup> C.F.R. § 440.130(d) (1990) defines "rehabilitative services" as "any medical or re-

tative services.<sup>52</sup> Every state, therefore, covers at least one of the services that could possibly provide Medicaid funding for augmentative communication devices, *i.e.*, physical therapy, prosthetic devices, or rehabilitative services.

Where a state provides speech therapy under Medicaid, it may be required to provide augmentative communication devices. The Eighth Circuit has held that where a state provides speech therapy, it is obligated to provide augmentative communication devices.<sup>53</sup> In Meyers by Walden v. Reagan, Iowa had excluded electronic speech devices from coverage under its Medicaid plan, arguing that it could properly exercise its broad discretion in determining the extent of medical services available under its Medicaid plan by excluding electronic speech devices from coverage.<sup>54</sup> The Eighth Circuit held,

Once Iowa chose to offer "physical therapy and related services," it bound itself to act in compliance with Title XIX of the Social Security Act and the applicable regulations in the implementation of those services. . . . The applicable regulation provides that Meyers is entitled to equipment provided by or under the direction of a speech pathologist that is necessary to correct her speech disorder. Thus Iowa cannnot arbitrarily exclude electronic speech devices from coverage under its Medicaid program.<sup>55</sup>

Furthermore, under the federal regulations, speech therapy is not restricted to those who are unable to speak "medically necessary" words; it is provided to individuals with speech disorders, regardless of the content of the speech. Thus, if a state provides only the most minimal augmentative communication device for those who are most severely speech impaired, it is limiting the scope of the services provided to those who most desperately need assistance while providing greater assistance to those who are less severely impaired.

The notion that services should be distributed according to the severity of the disability has been recognized by the courts interpreting other provisions of the Medicaid statute. In White v. Beal, 56 the Third Circuit found invalid

medial services recommended by a physician or other licensed practitioner of the healing arts. . .for maximum reduction of physical or mental disability and restoration of a recipient to his best possible functional level."

<sup>52.</sup> Arkansas, California, Connecticut, Delaware, Florida, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Texas, Utah, Vermont, Virginia, Washington, Wisconsin, and Wyoming. 3 Medicare & Medicaid Guide (CCH) ¶ 15,504 at 6505 (Oct. 1989). The District of Columbia also provides rehabilitative services. *Id.* The eleven states that do not provide rehabilitative services are: Alaska, Alabama, Arizona, Colorado, Georgia, Maryland, Nebraska, Pennsylvania, South Dakota, Tennessee, and West Virginia. *Id.* 

<sup>53.</sup> Meyers by Walden v. Reagan, 776 F.2d 241, 243-44 (8th Cir. 1985).

<sup>54.</sup> Id. at 243.

<sup>55.</sup> Id. at 243-44 (citations omitted).

<sup>56. 555</sup> F.2d 1146 (3d Cir. 1977).

state regulations that only provided eyeglasses for those suffering from pathology. The court noted that under the regulation, individuals with slight impairment of vision caused by pathology received eyeglasses, while those with more severe impairments caused by refractive error were denied eyeglasses.<sup>57</sup> As both *Meyers* and *White* demonstrate, the federal statute and regulations do not bar states from providing augmentative communication devices under state Medicaid plans and may require a state to do so if it provides speech therapy.

# IV. THE STANDARD FOR PROVIDING AUGMENTATIVE COMMUNICATION DEVICES

Many states provide Medicaid coverage for augmentative communication devices.<sup>58</sup> The critical question then becomes how to determine what type of device should be provided to a particular Medicaid recipient. States may try to provide only inexpensive devices that allow very limited communication.<sup>59</sup> For example, the New York State Medicaid agency has a history of denying approval for sophisticated speech communication devices and instead approving very limited devices.<sup>60</sup> States may also limit the availability of communication devices to Medicaid recipients, for example, by not providing sophisticated devices to individuals with mental retardation.<sup>61</sup> However, there is strong support in the federal Medicaid statute and regulations for the position that a Medicaid recipient is entitled to an appropriate device to correct her speech defect.

The regulations accompanying the Medicaid statute provide that each

<sup>57.</sup> Id. at 1152. There have been other cases where the courts have reached similar conclusions. See Ledet v. Fischer, 638 F. Supp. 1288, 1291 (M.D. La. 1986); Simpson v. Wilson, 480 F. Supp. 97 (D. Vt. 1979).

<sup>58.</sup> For example, from December 1987 through April 1989, six states (Iowa, Nebraska, New Jersey, New York, Ohio, and Wisconsin) and the District of Columbia provided Touch Talker and Light Talker devices through their state Medicaid programs. Memorandum from Elaine Koch, Prentke Romich Company, to the author (on file with Author).

<sup>59.</sup> At least one state Medicaid agency has taken the position that a state need only provide an augmentative communication device that enables the user to communicate basic medical needs. The New York State Medicaid agency has taken the position that "purchas[ing] a much more sophisticated device [than the Vocaid] only to allow the user to initiate a conversation or maintain an unlimited variety of conversation is beyond the scope of the Medical Assistance Program." In re Juan W., FH No. 1228167M, Agency Fair Hearing Summary, at 2 (N.Y.S. Dep't Health June 22, 1988).

<sup>60.</sup> My office, New York Lawyers for the Public Interest, Inc. [hereinafter NYLPI], is the legal support unit for Protection and Advocacy for the Developmentally Disabled in New York City and also does some general disability work. NYLPI has represented at least eight individuals who had been denied sophisticated augmentative communication devices. In one case, the Commissioner held that the device had been appropriately denied, but settled the case after NYLPI filed a case challenging that decision. In four cases, the clients were awarded the devices following fair hearings, and one case was resolved before the fair hearing. Decisions are presently pending in the two remaining cases.

<sup>61.</sup> See, e.g., Meyers by Walden v. Reagan, 776 F.2d 241 (8th Cir. 1985).

covered service "must be sufficient in amount, duration, and scope to reasonably achieve its purpose." Since services for individuals with speech disorders include corrective services, it is clear that one purpose of speech services, including equipment, is to correct speech disorders. A communication device that can be customized to meet an individual's particularized communication needs, and that will enable an individual to initiate and maintain a conversation, is necessary to correct the speech defect, as courts have recognized in analogous circumstances. 63

Furthermore, the Medicaid regulations specifically state that the rehabilitative services provided by Medicaid include services recommended "for maximum reduction of physical or mental disability and restoration of a recipient to his best possible function level." In order for an individual to be restored to "his best possible function level," it is necessary for that person to be able to initiate a conversation and maintain an unlimited variety of speech.

To illustrate this concept, individuals with disabilities other than those involving speech, such as hearing, mobility, and vision impairments, receive services to restore those recipients to their best functional level. Thus, many states provide hearing aids to correct hearing problems, not to provide "medically necessary" hearing. States provide wheelchairs and crutches to assist individuals with mobility problems, regardless of whether they need the devices to get to a hospital. States also provide eyeglasses to correct vision, not to provide "medically necessary" vision.

The Eighth Circuit Court of Appeals is the only appellate court that has addressed the issue of augmentative communication devices. In Meyers by Walden v. Reagan, 65 the Eighth Circuit held that once a state chooses to offer an optional service such as physical therapy and related services, it is required to comply with Title XIX of the Social Security Act and the applicable regulations in the implementation of those services. 66 The court found that under the applicable regulations, an individual with a speech disorder "is entitled to equipment provided by or under the direction of a speech pathologist that is necessary to correct her speech disorder." The court ordered that the case be remanded to the Medicaid agency to determine which electronic device was appropriate for Ms. Meyers, who was mentally retarded, since there had not been a determination by the agency as to which device was "most compatible with Meyers' needs and capabilities." The agency had contended that the

<sup>62. 42</sup> C.F.R. § 440.230(b) (1990).

<sup>63.</sup> See Mitchell v. Johnston, 701 F.2d 337 (5th Cir. 1983) (Texas must provide minimal dental benefits to meet federal standards); White v. Beal, 555 F.2d 1146 (3d Cir. 1977) (provision of corrective lenses based on cause, rather than effect, of disability violated Social Security Act); Simpson v. Wilson, 480 F. Supp. 97 (D. Vt. 1979) (Department of Social Welfare must provide eyeglasses and physician care to correct visual refractive error).

<sup>64. 42</sup> C.F.R. § 440.130(d) (1990).

<sup>65. 776</sup> F.2d 241 (8th Cir. 1985), discussed supra text accompanying notes 53-55.

<sup>66.</sup> Id. at 243-44.

<sup>67.</sup> Id. at 243.

<sup>68.</sup> Id. at 244.

Vocaid device met Ms. Meyers' needs and that the more sophisticated devices contained features that were beyond her capabilities.<sup>69</sup> On remand, the Medicaid agency settled the case by providing Ms. Meyers with the more sophisticated device.<sup>70</sup>

State laws may also provide support for the position that Medicaid funding is not limited to rudimentary devices. For example, New York state law specifically states that one purpose of medical assistance is to correct disabilities.<sup>71</sup> Therefore, necessary medical assistance includes an augmentative communication device which corrects a severe speech impairment, a significant disability which interferes with the capacity for normal activity and may cause acute suffering.

Considering the tremendous benefits of augmentative communication devices, one might well ask why state Medicaid agencies would deny a person with a severe speech impairment such a device. The answer is simple: cost. A computerized device that allows access to unlimited vocabulary may cost \$4,000 or more. Medical expenses have increased dramatically in recent years, and one way to hold expenses down is simply to deny approval to costly devices. While recognizing the importance of these speech devices, state Medicaid agencies may believe that the principal purpose for these devices is vocational or educational in nature and that other agencies, such as vocational rehabilitation agencies, should pay for them.

In light of the great benefits which result from enabling individuals with speech impairments to communicate verbally, the cost of communication devices is actually low compared with other medical services such as surgery, transplants, prescription medication such as AZT, and private duty nursing. Furthermore, such devices may enable clients with severe speech impairments to hold jobs, and therefore reduce or eliminate the costs of disability and other welfare benefits.<sup>72</sup>

### V. THE TREATING PROFESSIONAL STANDARD

Another approach is to look at the more general test for providing medical assistance under Medicaid. A strong argument can be made that the key to determining medical necessity is the opinion of the relevant treating health professional, and that, in deciding whether to fund a particular device, the

<sup>69.</sup> *Id* 

<sup>70.</sup> Telephone conversation with Thomas Krause, attorney for Ms. Meyers (May 15, 1989).

<sup>71.</sup> N.Y. Soc. Serv. Law § 365-a(2) (McKinney 1983) (Medical assistance means "payment of part or all of the cost of care, services and supplies which are necessary to prevent, diagnose, correct or cure conditions in the person that cause acute suffering, endanger life, result in illness or infirmity, interfere with his capacity for normal activity, or threaten some significant handicap.").

<sup>72.</sup> A 1985 Harris poll found that two-thirds of working age individuals with disabilities who were unemployed wanted to work but were unable to do so, in part because of discrimination and lack of transportation. Shapiro, *supra* note 4, at 22.

Medicaid agency should give great weight to the recommendation of the recipient's treating physician. The United States Supreme Court has recognized in dictum the importance of professional medical judgment by the treating physician in treatment of Medicaid patients.<sup>73</sup> The legislative history demonstrates that Congress intended medical judgments by treating medical professionals to play the principal role in determining medical necessity. The Senate Report stated that "the physician is to be the key figure in determining utilization of health services."<sup>74</sup>

The Eighth Circuit has embraced the treating professional standard in Medicaid cases. In the first case to raise the issue, *Pinneke v. Preisser*, 75 the court stated, "The decision of whether or not certain treatment or a particular type of surgery is 'medically necessary' rests with the individual recipient's physician and not with clerical personnel or government officials."

The treating physician rule — which gives greater weight to the medical opinion of the professional who examined the claimant than to other medical evidence — was first enunciated in cases involving Social Security disability benefits. The rule has been adopted by every circuit court of appeals except for the First Circuit.<sup>77</sup>

The treating physician rule provides that a treating physician's opinion is: "(i) binding on the fact-finder unless contradicted by substantial evidence; and (ii) entitled to some extra weight because the treating physician is usually more familiar with a claimant's medical condition than are other physicians."<sup>78</sup>

Although several courts have applied the treating physician rule to Medicare cases,<sup>79</sup> two district courts have suggested that testimony of a treating physician should not be given additional weight in Medicare cases because the physician "has much more of a personal interest in the outcome of Medicare cases; a rule giving great weight to [her] opinion in Medicare cases would

<sup>73.</sup> See Beal v. Doe, 432 U.S. 438, 445 n.9 (1977).

<sup>74.</sup> SEN. REP. No. 404, 89th Cong., 1st Sess. 46, reprinted in 1965 U.S. CODE CONG. & ADMIN. NEWS 1943, 1986.

<sup>75. 623</sup> F.2d 546 (8th Cir. 1980).

<sup>76.</sup> Id. at 550.

<sup>77.</sup> Schisler v. Heckler, 787 F.2d 76, 81 (2d Cir. 1986); Cotter v. Harris, 642 F.2d 700, 704 (3d Cir. 1981); Vitek v. Finch, 438 F.2d 1157, 1160 (4th Cir. 1971); Fruge v. Harris, 631 F.2d 1244, 1246 (5th Cir. 1980); Allen v. Califano, 613 F.2d 139, 145 (6th Cir. 1980); Allen v. Weinberger, 552 F.2d 781, 785 (7th Cir. 1977); Hancock v. Secretary of Dep't of Health, Educ. & Welfare, 603 F.2d 739, 740 (8th Cir. 1979); Murray v. Heckler, 722 F.2d 499, 502 (9th Cir. 1983); Wiggins v. Schweiker, 679 F.2d 1387, 1389 (11th Cir. 1982); Narrol v. Heckler, 727 F.2d 1303, 1306 (D.C. Cir. 1984). The First Circuit has yet to adopt the treating physician rule. See Sitar v. Schweiker, 671 F.2d 19, 22 (1st Cir. 1982) ("a treating physician's diagnosis is not necessarily entitled to more weight than that of a psychiatrist who examines the claimant only once").

<sup>78.</sup> Havas v. Bowen, 804 F.2d 783, 785 (2d Cir. 1986) (citing Schisler v. Heckler, 787 F.2d 76, 81 (2d Cir. 1986)).

<sup>79.</sup> See, e.g., Gartmann v. Secretary of U.S. Dep't of Health, 633 F. Supp. 671, 681 (E.D.N.Y. 1986).

create the opportunity for substantial abuses in the program."<sup>20</sup> Where a medical provider has a personal interest in the outcome of a Medicare or Medicaid case, as, for example, where the issue is whether surgery should be performed and the prescribing doctor expects to have her fee paid by Medicare or Medicaid, the question of bias is relevant to the determination and ought to be considered. In many cases, however, a treating medical professional will not have a personal interest. For example, a doctor would not necessarily receive any personal benefit from prescribing a communication device. Absent a showing of bias, the recommendation of a treating physician should be given substantial weight.

With respect to speech therapy, the federal regulations provide that the appropriate medical professional for providing services for individuals with speech and language disorders is a qualified speech pathologist or audiologist. Therefore, in making the determination as to whether to fund a particular augmentative speech device, the Medicaid agency should give great weight to the determination of the treating speech pathologist. Attaching such weight is particularly appropriate where the professional organizations of speech therapists have developed evaluation protocols for determining the appropriate augmentative communication system, <sup>82</sup> and the evaluation has been performed in accordance with the protocols. <sup>83</sup>

#### CONCLUSION

The ability to speak and thereby communicate with other people is vital to human beings. In the recent past, large numbers of people who were not able to speak because of disability, such as many with cerebral palsy, were misdiagnosed as severely or profoundly retarded and consigned to lives in institutions. Even today, many are still improperly diagnosed. Modern technology can provide severely speech impaired people with unlimited vocabulary and the means to communicate with others. These devices should be provided under state Medicaid plans.

<sup>80.</sup> Rendzio v. Secretary of Health, Educ. & Welfare, 403 F. Supp. 917, 919 (E.D. Mich. 1975); Weir v. Richardson, 343 F. Supp. 353, 357 (S.D. Iowa 1972).

<sup>81. 42</sup> C.F.R. § 440.110(c) (1990). For a speech therapist or pathologist, the pertinent professional qualification is a certificate of clinical competence from the American Speech and Hearing Association.

<sup>82.</sup> New York State Speech Language Hearing Association, Guidelines for Communication Aid Prescription and Reimbursement under Medicaid (Oct. 15, 1983).

<sup>83.</sup> New York State has been working with augmentative communication specialists to develop guidelines for reimbursement of augmentative communication systems that rely on an evaluation protocol that has been developed by the New York State Speech Language Hearing Association. The draft guidelines include a model worksheet for the evaluator and for the Medicaid review. Letter from Martin Ferguson-Pell to William Reynolds, Office of Health Systems Management, New York State Dep't of Health (Oct. 6, 1989).

