



CLINICAL REPORT

Prescribing Assistive-Technology Systems: Focus on Children With Impaired Communication

Guidance for the Clinician in Rendering
Pediatric Care

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ABSTRACT

This clinical report defines common terms of use and provides information on current practice, research, and limitations of assistive technology that can be used in systems for communication. The assessment process to determine the best devices for use with a particular child (ie, the best fit of a device) is also reviewed. The primary care pediatrician, as part of the medical home, plays an important role in the interdisciplinary effort to provide appropriate assistive technology and may be asked to make a referral for assessment or prescribe a particular device. This report provides resources to assist pediatricians in this role and reviews the interdisciplinary team functional evaluation using standardized assessments; the multiple funding opportunities available for obtaining devices and ways in which pediatricians can assist families with obtaining them; the training necessary to use these systems once the devices are procured; the follow-up evaluation to ensure that the systems are meeting their goals; and the leadership skills needed to advocate for this technology. The American Academy of Pediatrics acknowledges the need for key resources to be identified in the community and recognizes that these resources are a shared medical, educational, therapeutic, and family responsibility. Although this report primarily deals with assistive technology specific for communication impairments, many of the details in this report also can aid in the acquisition and use of other types of assistive technology. *Pediatrics* 2008;121:1271–1280

BACKGROUND

Communication skills are ranked as the concern of highest priority for adults with physical disabilities and, therefore, should be of paramount importance for children with impaired communication and their families.¹ Nearly 5 million children in the United States (approximately 15%) have some type of disabling condition.² Among children with disabilities who are attending school, >20% have significant communication impairments that are not attributable to impaired hearing.³ Conditions that can cause communication impairment include cerebral palsy, autism spectrum disorders, traumatic brain injury, and several genetic syndromes (eg, DiGeorge syndrome).

Many children and youth with special health care needs can improve day-to-day functioning with the aid of assistive technology, including alternative or augmentative technology. “Assistive technology,” the more general term, describes systems and devices that help alleviate the effects of a disability and, thus, improve function. An example is the use of orthotics (braces) for a child who has L4 paraplegia attributable to spina bifida. “Alternative technology” substitutes for functional impairments related to a disability (eg, adapted power wheelchairs for children who have quadriplegia). Lastly, “augmentative devices” are those that augment a deficient area of functioning but for which residual abilities remain. An example of this would be an electronic voice-output communication aid (VOCA), sometimes called a speech-generating device (SGD), to be used for a child who has dysarthria attributable to cerebral palsy. In this situation, although natural speech may be somewhat understood by family members, it is augmented when communicating with people who are less familiar with the child.

The most common context for alternative and augmentative systems is in the field of speech-language pathology (eg, augmentative/alternative communication [AAC] systems). According to an analysis of data from the National Survey of Children With Special Health Care Needs, approximately 2.1% of children and youth with disabilities have a need for “communication aids or devices”—AAC systems.⁴ The data also revealed that the needs for communication aids and devices were unmet for approximately 25% of these children.

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

Key Words

assistive technology, communication, children with disabilities, special health care needs, pediatrician, augmentative and alternative communication, communication impairments

Abbreviations

VOCA—voice-output communication aid
SGD—speech-generating device
AAC—augmentative/alternative communication
PECS—Picture Exchange Communication System
ICF—International Classification of Functioning, Disability and Health
AAP—American Academy of Pediatrics
IDEA—Individuals With Disabilities Education Act
EPSDT—Early and Periodic Screening, Diagnosis, and Treatment
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TABLE 1 Spectrum of Assistive Technology for Communication Impairments

| Type of AAC Technology | Characteristics | Examples | Advantages | Disadvantages |
|------------------------|---|--|---|---|
| Low-tech | Uses paper, plastic or similar materials | Simple picture/word boards or cards; PECS; eye-gaze picture board; visual scheduler or planner; adapted pens/pencils | Usually low cost; portable; personal; training is quick; readily acceptable to listener; rugged; no need for power supply | Very limited speed; very limited vocabulary; unable to use for long-distance communication |
| Mid-tech | Uses batteries for voice, text, or light output | Lighted on/off devices; "wrist communicator" (eg, with 2–10 stored vocal outputs); keyboard with display or printer; scanning light board (eg, with pictures) | Low-to-moderate cost; usually portable; usually personally owned; training is moderate; usually acceptable to listener; occasionally can use for limited long-distance communication | Limited speed; limited vocabulary; limited distance communication; power supply needed |
| High-tech | Microcircuits and microcomputer technology | Adapted laptop computers; commercially available VOCAs (dynamic displays, touch pads, or keyboards); individualized devices that use special inputs (eg, eye blinks) | Ease of progressing in skill levels; able to carry out extensive and efficient conversations; usually portable; often can use for long-distance communication (eg, telephone); able to connect to other devices (eg, for access to computer or for environmental control) | Moderate to very high cost; sometimes is not personally owned; power supply needed; training often extensive; listeners may need to have training |

See text for more details on some devices.

AAC is often erroneously thought to refer only to microcomputer-based and complex electronic devices. Although such electronic devices may be the best answer for a particular problem, they represent only the higher end of the spectrum of technology. Assistive technology, including AAC systems, can be thought of as low-tech, mid-tech, or high-tech.⁵ The costs for assistive technology also vary widely depending on the level of complexity and other factors. Although many low- and mid-tech AAC solutions are available to assist children with communication disabilities, this report focuses primarily on high-tech VOCAs or SGDs, because pediatricians are often asked to prescribe or approve the use of these more expensive devices.

CURRENT PRACTICE

Many types of AAC systems are available for use by individuals who have speech and/or language impairment (Table 1). Low-tech strategies include the use of objects, line drawings, and actual photographs or pictures of objects or persons to replace or augment spoken words. This is especially helpful for the development of communication skills of children who are nonverbal, particularly those who are unable to read.

Low-tech AAC also includes systems such as lists of words, phrases, or symbols that can be understood easily by others in many environments. By pointing to a desired target, simple communication boards or "flip-books" can be quite effective for face-to-face communication. For children who have visual impairment, three-dimensional objects that can be felt may be substituted for pictures.

Simple communication boards can be accessed through both direct selection and assisted scanning. In direct selection, the child directly touches or points to the desired target (eg, word, symbol). In partner-assisted scanning, the communication partner scans through the available

choices until he or she is stopped by a response from the child (such as an eye blink). For children with autism spectrum disorders, a systematic program called the Picture Exchange Communication System (PECS) has been developed and has gained increasing acceptance as a valuable tool for improving communication skills.⁶ In this system, children are taught to "exchange" laminated picture cards of the items or activities they are requesting for the actual items or activities themselves.

Mid-tech devices are typically battery-operated portable voice-output storage devices or devices that produce printed text. Devices can store a few recorded or digitized messages, such as "I want to see a movie," or multiple levels of messages. These levels are typically changed by the communication partners on the basis of the activity. When the desired button is accessed, the recorded message plays. Most mid-tech devices are accessed only through direct selection. Some mid-tech devices have scanning capabilities, accessed with a single switch.

Low- and mid-tech communication systems have inherent limitations. Vocabulary is limited by what is presented, and lengthy, novel messages are not feasible. Communication is usually slow and often more scripted than spontaneous or independent, and mid-tech devices require programming of scripted messages before the activity.

High-tech electronic AAC devices often incorporate the use of pictures or symbols, which may substitute for sentences or other groups of words, and are becoming more commercially available. High-tech AAC aids primarily have digitized or synthesized voice output (ie, are VOCAs or SGDs), although the methods of producing this voice output vary. Many high-tech devices use synthesized speech, an electronic voice that simulates that of a human voice. The use of a synthesized vocabulary allows for the creation of novel messages. Most comput-

erized systems have the capability to add digitized speech to specific messages. Unlike mid-tech devices, high-tech devices usually feature a dynamic display that changes with the input so that many levels of symbols, words, or lengthy messages can be stored for quicker retrieval, which improves both the variety of potential vocabulary items and independence in communication.

High-tech devices typically have the capability to have multiple access (input) methods ranging from direct selection on a touch screen to various types of scanning, mouse/joystick controllers, or encoding systems. Some computer-based devices can be accessed via eye gaze. For children who have both communication and physical disabilities, these alternative access methods are often needed. Systems that allow direct selection (eg, with a finger) are used with children who have adequate control of movements.

Single-function AAC devices (SGDs or VOCAs) serve as communication-output devices only. Some of the newer AAC systems, including some VOCAs, can also perform functions such as controlling the environment, accessing a telephone, or serving as a computer-access method.

The advantage of high-tech VOCAs is their expandability and flexibility. For children whose communication skills are likely to improve over time, the vocabulary in the VOCA can be modified to accommodate the advancing development and changing needs of the child. Thus, the skills of the child and capability of the device increase in tandem and promote communicative proficiency into adulthood. As an example, for a young child who has an ASD but is limited in communication by using the PECS, a VOCA may be helpful, because at least 1 report has indicated that VOCAs can increase communication skills in preschool-aged children with autism spectrum disorders.⁷

People who have normal speech are so accustomed to a high rate of speed that patience and appropriate training are necessary to communicate with an individual using AAC systems. This is especially true if the child is using a low-tech communication aid such as a symbol, letter, or word board. Although these methods are extremely slow and/or inflexible, they should not be abandoned. Depending on the child, they often are just as effective, if not more so, than high-tech devices in simple face-to-face communications and with multiple caregivers.

Another important consideration is that electronic devices are sometimes limited by their need for a power source, which inhibits their usefulness in situations in which battery power gets depleted. A lower-tech solution, such as a word or picture board, should always be available as a backup for high-tech AAC system users.

CURRENT RESEARCH AND LIMITATIONS

Much research has been published to demonstrate the benefits of early intervention for speech and language disorders, including using alternative systems such as pictures or sign language. Furthermore, research has demonstrated that the use of AAC systems does not decrease the use of natural speech.⁸ Currently, there is no consensus about the earliest age at which a child can

successfully use a more complex AAC device (eg, a VOCA). Some recent reports, however, have demonstrated successful use of complex devices with children younger than 3 years.⁹

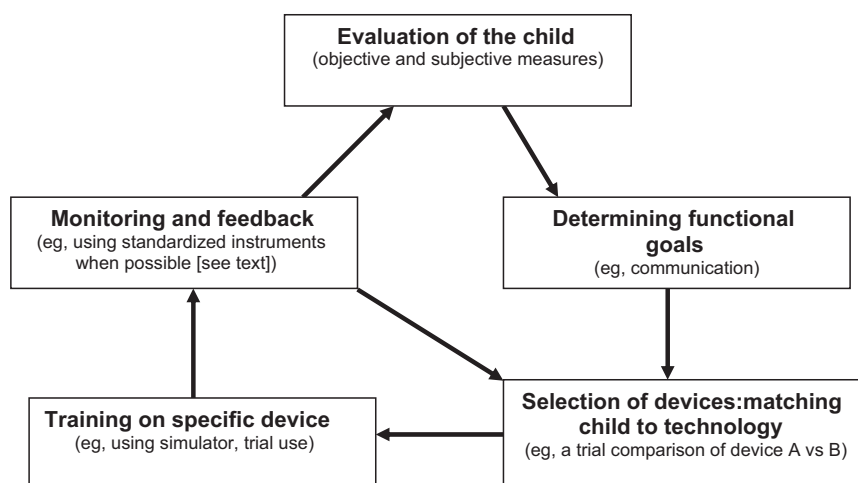
The use of electronic or computer-based AAC devices may promote natural language acquisition and cognitive development. For example, 1 study has shown that an AAC device will facilitate natural speech production in children who have some potential for speech.¹⁰ In addition, the use of communication aids offers opportunities for research into the interaction of people who are non-verbal (because of a disability) with those who are able to speak. An interesting but limited study by Beukelman and Mirenda¹¹ demonstrated the need to study the process by which AAC devices are selected and used. Their research suggested that if a child who has a severe communication impairment is successfully using an AAC device by the time he or she reaches the first grade, that child will participate more actively in classroom settings. Children who were skilled and comfortable with their AAC devices communicated more frequently with their typically developing peers. Additional research on AAC systems and children is needed, especially to determine if earlier exposure to communication aids will promote more facility in their use or other gains.

ASSESSMENT ISSUES

The assessment of a child who has a communication disorder and the selection of any assistive device should be performed by a team of knowledgeable professionals. This team approach is needed to properly evaluate both the child and devices to ensure the best match and to ensure that the device can be used effectively across environments and communication partners. Depending on the AAC device to be prescribed and the disabilities of the child, this team might include speech and language pathologists, physical therapists, occupational therapists, rehabilitation engineers, primary care and developmental pediatricians, psychologists, neurologists, physiatrists, special educators and other school personnel, child care workers, computer specialists, and others in conjunction with the family. In all circumstances, however, the major evaluator and decision-maker will be the speech-language pathologist. The team should be interdisciplinary and function collaboratively with ongoing discussions among the team members. Decisions of the team should be made jointly. Team members should provide or receive training and monitor the ongoing use of the device.

The basics of the overall assessment process for assistive technology are shown in Fig 1. This cycle usually needs to be repeated periodically as the child develops and his or her needs change. The assessment process for AAC should include consideration of the entire spectrum of AAC. One possible approach is to consider the use of low-tech devices and, if needed, to progress to mid-tech devices and, finally, high-tech devices. If a low-tech solution solves a particular problem, then more sophisticated technology may not be needed currently (but may be in the future). For example, a child with an autism spectrum disorder or other severe language disorder may derive more benefit from the simple PECS

FIGURE 1
The assistive-device–assessment cycle. (Adapted from Batshaw ML, ed. *Children With Disabilities*. 6th ed. Baltimore, MD: Paul H Brookes; 2007:563.)



than a complex VOCA, but if that same child outgrows the PECS, a sophisticated VOCA may become the most appropriate means of AAC.

The ultimate goal for using any AAC device is to achieve the highest possible functional communication. The first step, therefore, is to determine the person's current functional abilities, environmental situations, and personal preferences (Fig 1). One system that may be useful in such an assessment is the International Classification of Functioning, Disability and Health (ICF), specifically that for children and youth developed by the World Health Organization.^{12,13} Using this system, for example, one can classify and determine the extent of problems and strengths that a person has related to a communication disability that affects the ICF "activities and participation" domain and subcategories such as "communication" or "mobility." Using the ICF system may help to predict the effect that a specific device will have on a child in regard to each subcategory.

Standardized instruments for initial and follow-up assessments include the Functional Independence Measure, the children's version of the Functional Independence Measure (the Wee-FIM), and the Pediatric Disability Inventory.^{14–16} Environmental modifications, such as the use of assistive devices, have been shown to significantly affect these types of measures.¹⁷ Standardized language-assessment tests should also be used to determine progress in communication abilities.¹⁸ Caution is advised when using standardized tools to evaluate children using AAC systems, because they were not developed with these devices in mind.¹⁹ Accurate baseline measurements are crucial for evaluating functional changes over time after the introduction of any assistive technology, including AAC.¹¹

Children who have moderate to severe physical and communicative limitations are in particular need of the combined knowledge and experience of an interdisciplinary team, because many barriers to the use of assistive devices exist.²⁰ Factors that need to be assessed include current and future language needs, motor abilities and deficits, cognitive levels of functioning, vision and hearing functioning, communication partners, and environ-

ment and mobility issues. A major task for the team is to determine which movements the child can make consistently and how these movements can be used to control some type of device. Next, the team should determine the most acceptable, useful, and feasible output method depending on the child's needs and his or her communication partners. For example, output information could be displayed on a monitor screen, output by a printer, or presented as synthesized speech. Most of the time, multiple output types are preferred. Last, the child should be observed using various devices.

Educated opinions based on the successful experiences of other children who have similar disabilities using AAC can be quite useful. Using the aforementioned steps, the skilled speech-language pathologist should be able to select the devices that are most likely to meet the child's individual needs on the basis of his or her abilities and communication environments. Ideally, the child should have a trial period with a rented or loaned unit of the intended device before it is ordered or purchased. A 1- to 2-month trial gives the child and his or her family and the educators/caregivers the opportunity to be trained and to assess the child's ability to use the device in different settings to identify both the strengths and weaknesses of the system. These steps may reduce purchases of inappropriate devices. Partnering with a reliable technology center (especially at a university or nonprofit organization) is often useful, but these centers may be quite distant or have long waiting lists.

Studies have demonstrated that assistive devices may be abandoned shortly after they are obtained in one third of cases and that up to 75% of devices are never used successfully.^{21,22} Much of this can be attributed to lack of proper assessment and training. During the past 2 decades, however, methods have been developed to improve the successful matching of assistive devices to users (especially with adults [eg, "Matching Person and Technology"]).^{23,24} Similar methods have been used with older children and adolescents.^{25,26}

The physician or therapist who prescribes or recommends a VOCA or assistive devices in general must also accept responsibility for ensuring that the child and all

caregivers receive proper training and monitoring for the use of the device. Training is crucial for the successful use of any assistive device. Generally, the most appropriate approach to training and monitoring is to use the combined expertise of an interdisciplinary team of therapists and specialists.

A few tools and standardized measures are available to assist in the process of evaluating the efficacy and performance of assistive devices.^{27,28} One promising method was reported recently by a group that developed a 10-step framework, which includes input from parents, to help professionals obtain assistive technology for young children.²⁹ These tools are promising but are still in their infancy and require additional work.

Despite minimal data from controlled studies, methods are available to promote evidence-based and appropriate uses of assistive devices. A useful approach for determining the effectiveness of interventions in individuals may be the implementation of what has been called a "single-subject research design."^{30,31} This type of study involves the quantitative assessment of a child's baseline abilities, followed by repeat assessments after specific interventions.³² In the best of such studies, the assessments are performed by evaluators who are unaware of the intervention ("masked"); however, this is not critical. In the single-subject research design, the individual serves as his or her own control.

Although multiple-baseline studies may be difficult to obtain with children who are in a therapeutic or school environment, 2 or more types of interventions could easily be studied across time to determine which treatment or device seems to be the most effective. Figure 1 includes a "detour" between the steps of monitoring the use of the device and selection of device to allow for multiple baselines.

ROLE OF THE PRIMARY CARE PEDIATRICIAN

Identification, Referral, and Care Coordination

As part of providing the medical home, the primary care pediatrician should recognize communication disorders in children and make appropriate referrals.³³ Knowing how to contact experienced professionals and other appropriate community resources for assistive technology (which may be primarily for adults) is crucial. Children who need AAC systems require services for evaluation, procurement, training, and monitoring for devices and therapy programs. These particular services also need to be coordinated with other therapies and programs (eg, educational) that the child is already receiving and with the family. However, this integrative process can be confusing and overwhelming for the family. The pediatrician who is providing the medical home should develop a care-coordination process that involves all available resources (internal and external) to help families through this often-complicated process.

Primary care aspects of care coordination in the context of communication disorders involves 4 components: cooperating/assisting with the diagnostic assessment process to ensure proper diagnostic and prognostic information; helping with short-term and long-term plan-

ning by appropriate professionals, especially speech-language pathologists; assisting with the implementation of any of the parts of the plan, including helping to find funding sources for the purchase of devices; and working closely with the family and a team of professionals, mainly educational and speech-language therapists, to evaluate the effectiveness of the efforts being made and to ensure appropriate follow-up.

Although the primary care pediatrician should be closely involved with all 4 of these components of care coordination, the last step is particularly important. The primary care pediatrician may be the professional who is best able to evaluate the child's progress in relationship to the family's satisfaction or dissatisfaction. For specifics about providing care coordination and care management, a recent policy statement from the American Academy of Pediatrics (AAP), "Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs," provides additional information and resources.³⁴

Funding Issues and Access Regulations

Funding for assistive technology for children can come from schools; third-party payers including Medicaid and private insurance companies; or philanthropic sources. Roadblocks to funding AAC still exist, and many families have found that it is much easier to obtain funding for an expensive power wheelchair than it is for a less-expensive communication device. However, it is best to assume that funding will be provided, because, in the context of communication impairments, AAC is often necessary to overcome the limitations in functional communication caused by the impairment (just as a wheelchair overcomes the limitation of not being able to walk).

Beginning in 1973, several laws were passed that affected access to assistive devices for children with disabilities. First, Section 504 of the Rehabilitation Act of 1973 (Pub L No. 93-112) prohibited discrimination of children with disabilities and mandated educational programs for children with disabilities. This law was followed by the Education for All Handicapped Children Act of 1975 (Pub L No. 94-142), which required public education systems to provide a "free and appropriate education and related services" to meet the unique needs of every child with a disability. This educational service was to be provided in the "least restrictive environment" possible, an environment in which a child with a disability may interact with nondisabled peers. Section 602 of the law provides for the "use of instructional materials, including telecommunications, sensory and other technical aids and devices," to aid the child with disabilities to function more easily in the school environment.

The Technology-Related Assistance for Individuals With Disabilities Act of 1988 (Pub L No. 100-407, later amended as Pub L No. 103-218 [1994]), although written mainly to affect adults, also has proven to be quite beneficial to children. Called the "Tech Act," this law defined assistive technology and, more importantly, provided financial assistance to states to develop projects to

improve each state's delivery of assistive-technology devices and services. By 1996, after several revisions to the law and increased funding, 56 assistive-technology centers (1 in each state and US territory) were functioning.³⁵

The Education for All Handicapped Children Act was changed in 1990 to the Individuals With Disabilities Education Act (IDEA [Pub L No. 101-476]). The IDEA has increased services to children who have disabilities (birth to 21 years of age), including, by specific provisions in the law, appropriate assistive technology. This law was last reauthorized in 2004 (Pub L No. 108-446), and the sections related to assistive technology were essentially left intact.

The latest education law, the No Child Left Behind Act of 2001 (Pub L No. 107-110), does not specifically address technology but does include provisions that mandate "measurable educational improvement" for children who have disabilities.³⁶ In some instances, AAC technology may be needed to meet the measurable educational goals.

Recent Medicare regulations can be seen as a possible template for future mandates that may affect many more children. Medicare now authorizes that all people who receive Medicare benefits are entitled to receive "medically necessary" AAC devices, with 80% of the cost paid for by Medicare funds.³⁷ These new regulations, included in Part B of Medicare, cover only SGDs and provide for 4 levels of funding (up to nearly \$6500 for a device). Any adapted computer, however, would not be covered, because computers are not considered "dedicated" SGDs. Since final rulings in 2001, essentially all Medicare beneficiaries are entitled to an SGD if there is any "functional need" (eg, after a stroke) and a medical necessity letter is submitted by a physician (who does not need to be a specialist). Medicare also requires an evaluation and report by a "certified speech and language pathologist," although there is, as yet, no credentialing specifically for AAC by the American Speech-Language-Hearing Association.

Approximately 3 years ago, these same Medicare regulations were used to develop rules that cover funding for VOCAs for adults and children who receive benefits from the US Department of Defense (ie, the TRICARE program).³⁸ However, neither of these sets of regulations (Medicare and TRICARE) contain a requirement that the communication impairment be permanent.

In contrast to these 2 sets of regulations, Medicaid payments for AAC systems, being dependent on state laws and rulings, are extremely variable, and some states with strict limits for Medicaid rarely pay for AAC systems for children, especially expensive devices such as VOCAs. Medicaid funding is further discussed later in this report.

Educational System Funding

Funding for assistive devices and software will remain challenging for many school districts unless funding inequities among schools are resolved. It is fortunate that, as noted before, there are provisions within the IDEA and subsequent laws (eg, the Tech Act) and various legal opinions about these laws that specifically indicate that funding should be made available for "technologic de-

VICES" (including software) to help children who have special education needs. Although these statements are in public law, difficulties in finding the funds to pay for assistive devices and for other "educationally related services" will continue, at least for the foreseeable future. Additional information about these issues can be found in a statement from the AAP.³⁹

On occasion, schools have purchased VOCAs or other electronic communication aids for children with functional impairments. Unfortunately, these devices are sometimes kept at the school and are not allowed to be used at home. The Tech Act has tried to alleviate this problem partially by allowing Medicaid funding to be used by the school to purchase the assistive device. The Tech Act requires that such devices be allowed to be taken home with the child for "educationally related" purposes. In other words, for any device even partially funded by Medicaid, the school cannot prevent the child from using the device at home.

Debate continues whether AAC devices are "medically" or "educationally" necessary. If they could be shown to be medically necessary, it may be possible to obtain funding for these devices from health insurance companies or other third parties. In this regard, the use of AAC systems should lead to more efficient and accurate medical encounters (eg, improved describing of symptoms). If they are truly educationally necessary, perhaps school systems should be required to purchase the needed devices. Appropriate learning certainly depends on the exchange of information and efficient communication. This dichotomous debate is short sighted. Clearly, if one takes the view that health is about overall well-being and functioning, not just absence of disease, AAC is often medically necessary in many ways.

The complicated nature of education law terminology can sometimes cause knowledgeable parents to have unrealistic expectations that assistive devices, including AAC systems, must be immediately provided. Cooperative efforts between philanthropic agencies, school systems, and parents in some localities may be the best solution to finding appropriate funding. Parent groups and their allies may be able to lobby effectively for other sources of funding and convince schools of the need for appropriate assistive devices. The last resort, although laborious and slow, is to work with lawyers and the court systems if educational funding of AAC systems is not forthcoming for an identified educational need.

Third-Party Funding (Insurance and Medicaid)

As with wheelchairs, some AAC devices are increasingly being recognized as medically necessary forms of "durable medical equipment." For years, most private and governmental medical coverage programs have been willing to pay for the purchase of wheelchairs and gradually are beginning to fund other assistive devices, including AAC systems, primarily under their durable medical equipment benefit rules. In addition to requiring a doctor's prescription (and possibly a letter of medical necessity), most third-party payers also require a written evaluation report by a speech-language pathologist. It is unfortunate that some insurance companies

will not pay for any follow-up assessments or follow-up therapy critical to learning how to use the device (even when the school provides the funding for the device).

Although in all states Medicaid will pay for AAC devices, wide variation exists in state Medicaid requirements, which limit the ability to obtain funding. The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, which is a required part of every state Medicaid plan, could be used for funding of AAC systems, because under EPSDT, children are entitled to an “expanded scope of benefits.”⁴⁰ However, a number of recent reports have underscored continuing problems with implementation of EPSDT programs in most states.⁴¹ Some states have put considerable restrictions on the types, severity, or permanency of disabilities for people who can receive Medicaid payment for AAC systems. For example, Medicaid regulations in 1 state indicate that AAC is not covered for any person who can “functionally communicate verbally or through use of gestures,” and the person needs to have a “permanent” disorder.⁴² As mentioned before, pointing and gestures are very limiting and are not efficient communication methods.

The parent or guardian of any child who receives Medicaid benefits always has the legal right to challenge any decision made by a state Medicaid program, including denial of payment for therapy services or cost of repairing an AAC device. The appeal process involves requesting an administrative hearing, a process that varies from state to state. If there is an unfavorable decision made from this hearing, an appeal can be made to state and federal courts; such appeals have been successful occasionally.

Most state Medicaid programs will not fund AAC unless it is medically necessary to treat a permanent inability to communicate through oral speech. In some children who have communication impairments (eg, posttraumatic head injury), there may not be any “proof” that they are permanently disabled. Another source of reticence from Medicaid and other funding sources can be the minimal evidence for demonstrable short-term benefits. Long-term benefits could be substantial but may also be difficult to measure and may be mainly the result of improved mental health, self-esteem, and independence.

Referrals and Prescriptions

Pediatricians are often called on to make referrals, sign prescriptions, and write letters of medical necessity to help obtain funding both for the devices and the assessments. A letter of medical necessity should be written only after conferring with members of the team who have evaluated the child (especially the speech-language pathologist). This letter should state that the physician received the evaluation reports, reviewed the recommendations, and concurs that the recommended devices are medically necessary for treatment of the child’s communication impairment caused by the specific diagnosis. For some agencies, information about the child’s current status and expected outcome after using the device must also be included (but this information is often part of the report from the speech-language pathologist). The funding agency needs more than just a report of the physical examination or diagnoses. Government agencies, private

insurance companies, and charitable organizations all have limited funds, and requests that include the most complete and clear information are the most likely to be funded. Medicaid payers in many states and some insurance companies have set up specific requirements for a detailed evaluation report by a licensed speech-language therapist to accompany the prescription or medical-necessity letter that is signed by the physician.

Funding Overview

Obtaining funding requires perseverance. Sometimes, a request for an AAC device is denied because the funding agency has never had any experience with such a device. However, denials of funding by most agencies are subject to appeal. The appeal process in these situations should not be taken lightly. The denial letter may include reference to the specific statements made in the insurance policy. This can often be the starting point of an appeal letter by the family. Often, the speech-language pathologist, pediatrician, or other advocate can offer a supportive letter for this appeal. An appeal is most likely to be successful if it can be shown that a child can benefit significantly from using the particular device. Failure of an appeal can sometimes make funding for a particular device (or even any device) unlikely, if not impossible, for other children with similar disabilities. Therefore, a successful appeal can be used as an important precedent for future requests. AAC devices and their related professional services are relatively new and specialized, and they sometimes are not included on lists of approved products eligible for funding. Funding agencies may benefit from instruction about the potential of these devices to improve functioning and independence for children who have disabilities. Many companies that make AAC devices also have their own funding specialists on staff who can be helpful in dealing with insurance companies or other agencies.

Because funding for the purchase of devices and funding for training and monitoring in the use of AAC devices are difficult to obtain, the multidisciplinary team may need to develop insightful strategies to obtain funding for even the simplest low-tech devices. Literature is becoming available that focuses on the specifics of funding for devices and their long-term cost-effectiveness.^{43–45}

Unfortunately, there is no final answer to the conundrum of who should pay, and funding often requires a good deal of patience and creativity. In some cases, the final possible source of funding, when other options have been exhausted, may be local philanthropic organizations (eg, United Cerebral Palsy, Easter Seals, various social organizations). It is possible that additional improvements in regulations or expansions of state Medicaid-based programs (such as enforcing EPSDT rules) will also lead to more availability of AAC devices for children who need them. In addition, particularly if grass-roots efforts succeed, Medicaid rules may also be expanded to more closely parallel the rules now being implemented within Medicare (because of the recent regulations made in Medicare mentioned previously). However, this might lead, once again, to the apparently common situation in which Medicaid rules may some-

times be more permissive in funding AAC and other devices for children and youth with special health care needs than are insurance programs, which sometimes contractually consider them “noncovered” benefits (eg, for children who have autism spectrum disorders).⁴⁰

Advocacy Information

Technology advances quickly, and it is rare that a pediatrician can stay current with all new developments. Pediatricians, however, should serve as informed advocates. Families of children with disabilities may have very high expectations about AAC and other assistive technology. They may try to find answers to their concerns and questions with or without support from health care professionals. Pediatricians often have a critical role in this process, because caregivers, patients, or allied health professionals may request their opinion or prescriptions for some of these devices. To be able to provide realistic and appropriate answers, pediatricians should keep generally informed about what is being developed and marketed and, more importantly, what local resources are available to provide more information and access to a proper assessment.

Fortunately, there are readily accessible sources of information that can provide current information about assistive technology (see Appendix). An important resource for specific materials, such as examples of medical-necessity letters, is the AAP National Center for Medical Home Initiatives for Children With Special Needs. The National Assistive Technology Technical Assistance Partnership oversees the federally mandated but state-funded “Assistive Tech” projects. These state projects are excellent information hubs and can refer individuals to appropriate service providers. Various organizations that deal with children with disabilities, such as the Council for Exceptional Children and others, have also developed services that can be used to obtain references and abstracts about many facets of disability, especially with regard to school-related services. There are increasing numbers of Internet sites that offer resources for using assistive technology with children, although some of them are thinly veiled advertisements from companies or groups that may propose “alternative therapies.” The Appendix contains a list of selected sources for information retrieval.

CONCLUSIONS

Children with disabilities can benefit considerably from assistive technology, perhaps sometimes more than adults with similar problems, because assistive technology can help to maximize children’s developmental potential. Financial and societal barriers currently prevent the equitable distribution and application of this technology, especially for AAC systems. Many jobs are now becoming available for adults who have physical and communication disabilities. Jobs such as editing, writing, and computer applications do not depend on speed of output as much as good judgment and reasoning abilities. Children who have severe physical and communication impairments but good cognitive skills should be able to look forward to a degree of independence in adult life with the possibility of an occupation that is personally rewarding and provides financial

security. Their ultimate success, however, depends on what tools they are given as children.

The future will bring many new and useful devices that can help a child who has a communication disability be more functional. Appropriate use of the entire spectrum of AAC systems and devices for children who have communication disabilities is needed, is supported by several federal and state laws, and is ethically proper.

GOALS AND GUIDANCE

1. As part of the medical home, pediatricians should identify all children who have communication problems and refer them for appropriate evaluations.
2. As a part of providing the medical home, primary care pediatricians should recognize their roles in advocacy and care coordination for children who have communication disabilities.
3. Pediatricians should ensure that all children with communication disabilities have access to appropriate AAC systems, including complete evaluations, training, and monitoring by professionals (eg, speech-language pathologists and occupational therapists) and acquisition of appropriate devices.
4. Pediatricians should advocate for the appropriate funding of AAC and related services for children with communication impairments at local, state, and federal levels. Barriers to funding must be addressed. There is a critical need for Medicaid funding of AAC and AAC evaluations to be based on a more uniform policy and funding stream, such as what has recently occurred with Medicare Part B, rather than extremely variable state-by-state decisions.
5. Care-coordination efforts by pediatricians and other health care professionals, a crucial part of the provision of a medical home, should be paid for by third-party payers.
6. All pediatricians, including subspecialists, who are vital to the child’s medical home, university and tertiary care centers, state Title V agencies, school districts, state agencies, and insurers should work cooperatively and collaboratively to improve appropriate access to AAC devices and programs.
7. Pediatricians should provide guidance, information, and support for families of children with communication impairments to act as advocates and care coordinators for their children.
8. Pediatricians caring for children with communication disabilities should assist parents in discussions with school personnel and child care personnel to ensure that any communication system or device that is being used in educational settings can also be used in the home and other family-oriented settings.
9. Pediatricians should advocate for research to be directed toward new approaches to the assessment of children who have communication disabilities and evaluation of the effects of using AAC devices (especially VOCAs).

10. Pediatric residents should receive appropriate training in the assessment of children who have communication disabilities so that they are properly prepared to diagnose, manage, and coordinate care for children with communication disabilities and advocate for these children and their families.

APPENDIX: RESOURCES

National Organizations

American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, MD 20852; www.asha.org; 301-897-5700

National Institute on Deafness and Other Communication Disorders, National Institutes of Health, 31 Center Drive, MSC 2320, Bethesda, MD 20892-2320; www.nidcd.nih.gov; 800-241-1044

Internet Resources

AAP Department of Practice, Division of Health Care Finance and Quality Improvement (a resource to assist pediatricians with helping families to obtain coverage for needed services including speech/language and other therapeutic services); <http://aap.org/moc/reimburse/codingbrvsresources.htm>

AAP National Center of Medical Home Initiatives for Children With Special Needs (training programs and materials and other resources for pediatricians including materials to help with care coordination for children who need assistive devices); www.medicalhomeinfo.org/training/compindex.html

Assistive Technology Law Center, SGD Funding Solutions (provides information about resources and programs that provide funding for AAC, especially SGDs); www.aacfundinghelp.com

ATOMS (Assistive Technology Outcomes Measurement System) Project (an academic, research-based resource for measuring outcomes of the use of assistive technology); www.r2d2.uwm.edu/atoms

Council for Exceptional Children (a site with broad uses including references to laws and links to agencies [including CEC-Canada]); www.cec.sped.org/AM/Template.cfm?Section=Home

Hattie B. Munroe Barkley Memorial Augmentative and Alternative Communication Centers (resources and links for AAC, including specific Web sites for AAC uses with young children and early intervention [the YAACK program]); <http://aac.unl.edu>

National Assistive Technology Technical Assistance Partnership (NATTAP) (provides technical assistance to the 56 state and territory assistive technology programs as authorized under the Assistive Technology Act of 1998); www.resna.org/taproject

National Organization Caring for Kids (NOCK) (provides grants for AAC devices for children with severe communication impairment caused by a chronic illness [another part of NOCK provides wheelchairs]); www.nockonline.org; 253-851-6625

Net Connections for Communication Disorders and Sciences. An Internet Guide (by Judith Maginnis Kuster). This site includes valuable resources for professionals and

students in communication disorders and sciences as well as for persons with communication disorders. www.mankato.msus.edu/dept/comdis/kuster2/welcome.html

United States Society for Augmentative and Alternative Communication (an "organization dedicated to supporting the needs of people who rely on AAC devices, as well as the professionals, [and others] . . . making up our community"); www.ussaac.org

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