3. Assistive Communication Systems
CLASSIFICATION OF ASSISTIVE COMMUNICATION SYSTEMS

Communication systems for the nonspeaking may be unaided or aided by manmade devices. Unaided systems are often also described as manual, gestural, or supplementary. While they have the advantage of needing no external materials, they are of little use to persons whose arms and head are paralyzed or who cannot control their movements. Some of these people can blink their eyes to signify yes or no, and become quite adept at conveying meaning by systematically changing their direction of gaze and focus. But this hardly constitutes more than marginal communication unless the receiver knows the sender’s signals and can interpret them. For those who use sign language, face-to-face encounters with persons also familiar with sign language are required. And, as is true of virtually all unaided systems, sign language cannot be transmitted either in writing or by most telephones.

Aided systems range from simple language symbol or alphabet boards without any mechanical or electrical parts that may be made or purchased for only a few dollars, to electronic devices—some computerized—that may have price tags of $5,000 to $6,000 or more. Whether simple and inexpensive, or costly and complex, or somewhere in between, all aided communication systems require the user to tell the equipment what to say. This is accomplished in one of three ways.

The first is direct selection. An ordinary mechanical or electric typewriter is a typical direct selection device, but one ill-suited to the many people with severe speech disabilities secondary to severe disabilities. Accordingly, direct selection communication aids for this population may have keyboards that require less manual dexterity than the ordinary typewriter keyboard, or may have matrix displays on their surfaces of pictures, symbols, letters, groups of letters, or phrases, or some combination of these, that the user points to or presses on as the information he or she wishes to convey.

Although direct selection devices are far from as rapid as normal speech and so are somewhat frustrating to even the most adept users (the more so because speaking persons are often too impatient to let users complete their thoughts), they are still intrinsically the fastest way for nonspeaking persons to communicate. Some electronic direct-selection devices have computerized memories that make it possible to compose a fairly lengthy message in advance and a printing capability that releases this product from storage on the user’s command. Others make a modicum of informal “conversation” possible by printing short messages while the listener is present, or by displaying such messages on small screens in light-emitting diode or liquid crystal display lettering. Some machines have both print and display capabilities.

Because of their physical limitations, however, many nonspeaking persons cannot transmit their thoughts to others by direct selection. Even if they are supplied with an input link to the device (often called an interface), such as a foot or tongue operated switch, a breath-operated sip-and-puff switch, a joy-stick, or a wand or optical light pointer (worn on a band or straps around the head), they simply do not have sufficiently fine-tuned motor control. For these individuals, electronic scanning devices that make the selection on the user’s behalf are often more appropriate. With these devices, the user scans a “menu” of possible choices and selects one by means of a simple yes-or-no response. Some of these scanning devices can also be used in direct selection mode.

Scanning communication devices differ in detail, but all of them present the user with: 1) components of vocabulary -i.e., numbers, letters, groups of letters, words, phrases, pictures, symbols, etc., or some combination of these; and 2) an indicator mechanism on the display that serves as a pointer. With an input attachment for this kind of selection (and sometimes without one,
for example, if the person can use his elbow or balled fist for input), nonspeaking persons can have these communication aids sweep the field until the desired place on the display is reached and then simply instruct the pointer or indicator to come to a stop. Again, this makes person-to-person interactions possible. Some of these devices also either have printing capabilities or can be connected, for an additional investment, to separate hard copy printers.

A third form of personal communication aids are those that operate by encoding. That is, their inputs go into the unit in the form of numbers, for example, and these are then electronically converted into written or synthetic speech outputs. As a general rule, encoded systems offer the user larger vocabularies and more flexibility than direct selection on scanning units and more speed than scanning units. Their disadvantages are that: 1) some are not portable though this may change as newer models employ miniaturized computer components, and 2) it generally takes longer to learn to use these units proficiently and requires a considerable amount of cognitive ability. For example, encoded systems may entail activating two switches simultaneously or several switches sequentially, making their operation somewhat complex.

Still, an encoding system is probably preferable to either direct selection or scanning because of its speed and versatility, providing the user is sufficiently motivated, intelligent, and cognitively intact. Professor Wesley R. Wilson and his colleagues at the University of Washington’s Child Development and Mental Retardation Center developed one prototype encoding system for severely physically disabled clients of normal intelligence who can spell at least at a grade 4 level. The basis of this system is Morse code (23,25). Properly selected subjects—most of them cerebral palsied children—have been able to learn it with 80 to 90 percent or better accuracy within a month. The inherent drawback of the code—that both sender and receiver must know it—is overcome by a microprocessor that converts the dots and dashes into printed letters. The system can also be supplied with an attachment for synthetic voice output.

The core of this Morse code communication system is a computer mounted on the base of the client’s wheelchair that is linked to two head switches, one to signal dots and the other to signal dashes. The switches activate a second communicator unit fitted to the front of the wheelchair (it swings out of the way when the user wishes to move from the chair) that has a liquid crystal display screen—visible on one side to the user and on the other to his listener—and a small printer for hard copy. Other capabilities of the system include an emergency call system, environmental controls, an optional synthetic voice output, and an interface for Apple computers. When programmed with special software, Apple computers can increase the speed of communication by permitting the computer mounted to the wheelchair to guess, with some accuracy, words that the user has started to spell. (The user can cancel the message if the computer’s guess is incorrect.) The entire system is powered by rechargeable battery. Once the user is in the chair and someone turns the system on, all the system’s features are at the user’s command.

Communication systems for people who are nonspeaking and severely physically disabled have been discussed thus far with regard to whether the systems are aided or unaided. They can also be considered from another perspective: as designed from the outset for a disabled population or as designed primarily for able-bodied users but usable, if modified, for the nonspeaking neurologically or neuromuscularly impaired.

There are probably well over a hundred systems of the first type, many of them one-of-a-kind models made in home workshops for a family member or friend. But no more than 40 to 50 of them have been marketed, and their sales volumes have been small, numbering at most in hundreds of units per year. (This will be discussed further in ch. 4.)

Systems designed primarily for able-bodied users include some battery-powered devices that can be used by nonspeaking disabled people without modification, providing they have sufficient manual dexterity and muscular control to operate them: the Texas Instruments Corp.’s synthetic educational aid, “Speak and Spell” (which has a
retail price of about $60), and its learning aid, the “Language Tutor” (which has the same synthetic voice component and sells for about $1.50) have been employed by some of the nonvocal both for face-to-face conversations and to convey information over the telephone—though their use for the second purpose is cumbersome.

The more recently introduced Sharp Electronics Co. Memowriter, widely advertised to executives in airline flight magazines, appears to serve the same purposes as the Canon Communicator discussed earlier: both are portable keyboard devices that print short texts on a narrow roll of paper tape. The Sharp product, at $130, costs less than a third of the $594 Canon, is smaller and lighter, and—with its calculator functions and 40 shortage keys for phrases—is more versatile and sophisticated electronically. But the Canon Communicator, unlike the Sharp instrument, is available from the manufacturer with keyboards for the motor-impaired or with a pencil-like headstick for those who cannot use their fingers at all. However, an augmented keyboard for the Memowriter is made in Canada.

Two other developments may open even greater avenues of communication for those who can neither speak nor write by normal means.

One rather recent development is the design of products for the handicapped that can be mass produced but readily customized by the manufacturer for any given user. Such products represent a middle ground insofar as they are intended for a market that is smaller than that composed of able-bodied people but larger than that composed only of severely physically disabled persons who cannot speak. Thus, these products have some potential commercial advantage.

The Ability Phone terminal, made by Basic Telecommunications in Fort Collins, Colo., exemplifies this design trend. The purpose of the unit is to permit a severely disabled user to receive and transmit information by telephone with much the same freedom of an able-bodied caller and to further the disabled user’s independence by providing an electronic reminder, a calculator, and a dial-for-help capability. Relying on microprocessors, the unit can also turn on or off as many as 15 lights and appliances.

The unit’s versatility lies in the compatibility of its core with an extensive selection of accessories. The unit can be ordered with precisely the options a client needs. These options include a braille keyboard, a synthetic voice output, and a variety of types of operating switches, microphones, and handsets among others. The base price of the unit which became commercially available in September 1981, is $2,335; the total cost of the system, depending on the accessories selected after client evaluation, can run as high as $3,300.

The second important development is the design of products primarily for an able-bodied person that can also be used by severely handicapped persons with a variety of disabilities. Unlike the core unit of the Ability Phone which is designed primarily for handicapped persons, the core unit of these products is designed primarily for the far larger market of able-bodied consumers.

The preeminent example of such a system is the relatively inexpensive personal computer (retailing at about $2,000 or less), such as those marketed by Apple and Radio Shack. With relatively simple modifications, these microprocessors can be made not only the basis of communication systems for the multiply handicapped nonvocal, but can also operate environmental controls (e.g., light switches, appliances, radios, television sets, and electronic door openers). If the price of personal computers continues to drop as expected, it should become possible to provide these users many capabilities and for a fraction of the cost it now takes to provide them separately. Both Apple and Radio Shack computers have good reputations for reliability and local repair service. But, as this was written, Apple machines had the edge because workers in the handicapped field found their electronics easier to modify.

As microcomputers have become mass market items, they have attracted the attention of computer hobbyists as well as rehabilitation professionals. These amateurs can be enlisted to adapt commercially available educational and recreational software programs for the needs of disabled individuals, to write programs for the disabled population from scratch, and to write programs that speech and other professionals can use for testing.
This use of small computers may provide a psychologically healthy aura of normalcy and sophistication to physically disabled nonvocal individuals and suggest to them that computer operation and computer programming are potential sources of employment. It may also facilitate their academic work. The Maplewood Apple 11 Computer Project, which began in 1978, demonstrates the last benefit well (25).

Maplewood is a special education facility for moderately to profoundly handicapped children that serves 36 elementary and junior high schools in the Edmonds School District, just north of Seattle. Some of its clients attend regular classes at regular schools and go to Maplewood only for support services (Group A). Other clients attend classes in regular schools, but in classrooms set aside for the handicapped, and go to Maplewood for support services (Group B). Still others are sufficiently physically and mentally disabled that they go both to school and get their support services at Maplewood (Group C).

Nonvocal children are found in all three groups. Such children in Group C—of mental age 12 to 24 months and thus, severely cognitively impaired, are being motivated by motor-training computer games. Their counterparts in the other two groups were exposed to the Apple 11 through computer games and then, having gained adequate mastery of the essential operative techniques, have since used it for academic work as well. Though the degree of sophistication with which each group could use computers varied, computers have clearly helped all three of them come closer to achieving their maximum potentials.

The progress of the Group A students has been particularly dramatic. One of the children was delayed by his severe physical limitations in controlling the computer, an obstacle that has only recently been overcome. But the other three children—in grades three to eight—have made substantial gains in reading, spelling, and arithmetic and have progressed to the point where they can use commercially available educational software programs instead of individually tailored ones. Since relatively few educational software programs are marketed for children of preschool or early elementary school levels and all three of these youngsters are now beyond those points, this is a special boon. When one of the Group B boys had the opportunity to use one of Maplewood’s Apple II Computers at home during the summer, he fairly quickly became able to use commercially available educational software programs, too.

In the interest of the best possible fit between client and communication systems, the assessment begins with determining the strength, as well as the disabilities, of the prospective user. The composition of assessment teams varies, but may include—in addition to the client—professionals from the following disciplines: speech-language pathology, audiology, linguistics, psychology, physical therapy, occupational therapy, rehabilitation engineering, social work, and education. (Note: the terms speech-language pathologist and speech therapist are interchangeable, but the former term is preferred.) The American Speech-Language-Hearing Association’s official position on assessment for the severely physically disabled nonvocal population is:

The central role in initiating and coordinating the services of this team should be taken by the person most likely to initiate the recommendation for an augmentative communication system, based on his/her evaluation of the client’s oral motor performance, language competence, and communication needs. Further, the person needs to possess the knowledge of language development and communication interaction which will be essential to the client’s success in augmentative communication. In most cases the speech-language pathologist would be the person who best meets these requirements.

One goal is to provide an interface device (between the person and the communication device) that requires the least effort and provides maximum reliability. A movement that is too difficult or tiring will cause frustration by being needlessly slow or inaccurate, and the extended use of an abnormal reflex pattern can itself produce physical deformity. Thus, the assessment also encompasses measuring the client’s range of motion and determining with some precision to what degree he or she can “fine tune” the movement or movements that might be used as the link between the body and a communication aid.
The choice to be made among many types of interfaces (different sorts of switches, keyboards, head wands, mouthsticks, nightsticks, etc.) often makes assessment difficult. One systematic approach to the problem has been that of Margaret R. Barker of the Rehabilitation Engineering Center, Children’s Hospital at Stanford University; and Albert M. Cook of the Assistive Devices Center, California State University, Sacramento (2). In evaluating the physical ability to control assistive aids, these investigators and their colleagues make an inventory of all the anatomic sites where a person can demonstrate purposeful muscular movement and then have the person use those sites to perform such tasks as grasping or squeezing an object. Other factors being equal, hand and finger sites are preferred to sites on the head, and sites on the head to those on the feet. Sites on the legs and arms are least favored because, in general, muscles there are least suited to finely controlled movements.

Once one or more promising anatomic control sites are identified in this manner, the next steps are to determine:

1. how much control (i.e., range and precision of motion) the client can demonstrate with each site;
2. which types of interfaces work best for the person at the potential control sites; and
3. how rapid and accurate the client’s movement is at each site and interface combination, and with each combination how quickly the client tires.

This constitutes the first comparative testing of site-interface combinations, which are thus rank ordered. Together with the client’s preference, this testing helps the rehabilitation team to avoid guesswork in recommending interface choices and to clearly delineate what tradeoffs should be considered before a final decision is made. Barker and Cook believe that followup evaluations at 3 months, 6 months, and 1 year are critically important. If the initial choice of interface proves disappointing, these evaluations provide the opportunity for adjustment or change.

Considering the client’s posture is no less important than considering the interface. Many severely physically disabled nonspeaking people use wheelchairs. This means that unless the client is properly positioned in the chair (by cushions, padding, restraints, straps, etc.) and the placement of the communication aid is made appropriately, the client may be unable to use the aid efficiently.

Unfortunately, many of the current generation of portable communication aids are too bulky, too heavy, or both to be used by those physically disabled nonspeaking persons who can walk. Even when an aid is small enough and light enough for such a client to use when he or she is ambulatory, careful attention must be given to exactly how the client will wear or carry it and to its durability. Ambulatory people with movement disorders are subject to inadvertent collisions with inanimate objects and to frequent falls.

In fact, ease of maintenance and access to timely repairs at moderate cost can make the difference between appropriate and inappropriate devices for all nonspeaking clients, regardless of whether their units are portable. Because many of these devices may be made or serviced far from where the clients live, reliability is also a factor that the assessment team should not overlook. Few, if any, school districts have repair and maintenance staff trained to service high-technology, computer-based communication aids making this the responsibility of manufacturers and distributors who are not always in a position to do the job. Of course, even where there are such services for students, they are not usually available to nonstudent clientele.

Assessment is also directed toward testing a client’s actual or potential language skills and his or her style in responding to verbal stimuli and in arranging objects, pictures, symbols, words, or letters into larger units of communication. A client who is to use a scanning device, for instance, must be able to remember what he or she is looking for long enough to find it on a display of multiple-choice items arrayed in rows and columns. No matter what type of communication aid is considered—except perhaps if it is to provide only a choice of “yes” or “no”—the user must be able to discriminate between like and unlike items, to put ideas in logical sequence and to classify.

An important aim is to determine (regardless of how the client was previously able to commu-
nicate) whether the client has receptive language abilities, to what degree, and how best to utilize them. Some nonspeaking persons, for example, are at least temporarily incapable of using the alphabet, and for them a pictorial language like Bliss symbols—also called Blissymbolics—may be either the best language they can master or a way station toward later learning to read and spell (17,24).

Blissymbolics is a graphic, meaning-based system, in use in 15 countries, that enables anyone who can point to a symbol display, or control a device that presents these symbols, to communicate. Because the user selects and transmits the meaning elements of the message—i.e., the symbol—he need not know how to read, spell, or analyze words into their phonetic components. And, because a written word or group of words always accompanies the message, Blissymbolics can be understood by any receiver who can read. Other clients may already know how to read and spell or may show immediate promise of being able to learn to do so. Without appropriate optimal assessment of such language abilities, the chances of an optimal match between client and communication system are remote.

It is important to remember, too, that advances in communication aids are to be expected and that the needs of nonspeaking persons may change over time. For those whose disabilities are likely to be stable—e.g., most persons whose lack of speech is congenital—a trade-in or refitting option could enable them to take advantage of technological improvements as they come along. The communication system that serves a 5-year-old cannot be expected to serve an older child or an adult. Similarly, persons with such progressive disorders as multiple sclerosis or amyotrophic lateral sclerosis (ALS) who today can function with one kind of communication system may need quite another kind as their condition deteriorates, something that can happen in the span of only a few months. Yet insofar as the author could determine, few manufacturers of personal communication aids make provisions for trade-ins or component refitting, and there are few loan or rental banks of these devices organized by hospitals, clinics, voluntary groups, or other community organizations.

Thinking differs as to when in the assessment process it is best to even provisionally expose a client to a choice of commercially available communication aids. In a study of 16 ALS patients in Britain, Perry, Gawel, and Rose recommended “that a ‘library’ of aids be available to patients so that a good choice may be offered and, as the disease progresses and manual dexterity diminishes, they may exchange one aid, which is no longer appropriate, for another that meets their needs more realistically” (34). This is also the view of many workers at U.S. education and rehabilitation centers who believe that, whatever the reason for their clients’ inability to speak, having an array of aids on the premises would not be only advantageous to them, but would also serve to familiarize the staff with the devices on the market and new ones as they are introduced.

There are others, however, who believe such a “library” of aids requires too much financial outlay or is undesirable on other counts. For instance, Bruce Gans, Director of Patient Services at New England Medical Center’s Rehabilitation Institute in Boston, believes that “to have an array of technical equipment is a very restrictive approach to the problem (of assessing nonspeaking persons because) you immediately presume that your universe of options is right in front of you. . . . First of all, one must define what the patient’s real needs are” (14).

At The Children’s Hospital in Boston, Howard Shane, Director of Communication Enhancement, says that a library of devices would not only be expensive and unnecessary, but would take up too much space. Instead, his unit asks distributors to supply videotapes of what their products look like and how they operate so that clients (some of the adults) and their parents can view them. If it is decided that one or another aid may be appropriate, a trial period is arranged before a recommendation is made to purchase (41).

Obviously, this is a controversial topic. It should be reported, therefore, that the Institute of Neurological and Communicative Disorders and Stroke (a part of the National Institutes of Health) has awarded Richard Foulds of the New England Medical Center a contract “to develop a prescriptive assessment system to determine the
characteristics of the device most suitable for a particular patient; to review, using computer software, the various devices available; and then to select that which best matches the necessary specifications. This approach does not require a center to have a large selection of devices on hand. Completion of the project is expected in 1985 (32).

Meanwhile, Shane, like Gans, believes that not having a variety of devices on the premises of an assessment center minimizes the risk of prescribing one when it may be inappropriate or premature. He and his colleague, Anthony S. Bashir, have been particularly interested in persons—most of them cerebral palsied—whose communication disorders are congenital. In this connection, they have developed a branching type assessment matrix for recommending a device or not that takes into account:

1. the age, physical, and intellectual status of the client;
2. other factors, such as whether or not the client has previously had speech therapy; and
3. the family’s willingness to allow the child to be fitted with an augmentative communication system (42).

If, despite speech-language therapy, for instance, a 3-year-old is still unable to imitate speech and word sounds with some accuracy, he or she may make greater communication strides by being introduced to an alternative system, which may later facilitate speech development. In a study done at the University of California, Los Angeles, in fact, Laura Meyers found that starting such children with communication aids encouraged development of language and that as the children developed spoken words they dropped them from communication aid use because the spoken word was so much faster (27,28).

On the other hand, many parents find it hard to accept the possibility that their child may never talk. Thus, while it is in one sense to provide a communication aid immediately, professionals sometimes find it prudent to delay the description pending more counseling for the parents. However, as children develop spoken words, they tend to drop them from communication aid use, which parents should be told.

Just as philosophies differ as to whether assessment centers should have libraries of commercially available devices on hand, they also differ as to whether—other considerations being equal—a display or voice output is preferable. Although the situation is subject to change, all off-the-shelf commercially available devices now offer only one or the other capability.

Some speech professionals believe with Professor John Eulenberg of the Artificial Language Laboratory of Michigan State University that, if a client is to have only a single mode of communication, voice output is more likely to facilitate the normal socialization of nonspeaking multiply handicapped persons of any age. Furthermore, most children prefer spoken output. But others are of the opinion that, for children, especially, such a choice is unwise.

Gregg C. Vanderheiden, Director of the Trace Research and Development Center for the Severely Communicatively Handicapped at the University of Wisconsin is among those who represent that opinion (50). According to Vanderheiden,

It would be good to have voice output as a part of any system. But the key is that, although you can use writing for conversation, you can’t use conversation for writing. And, besides, no current voice output system approaches the speed of conversation anyway. Thus, if you are going to have any educational work, any kind of learning, you need to have a system that will enable you to write. In fact, the thing we have to watch out for as voice output systems become cheaper and cheaper is that we don’t end up with voice output aids only, thereby ignoring the other communication needs of physically disabled nonspeaking youngsters and so sentencing their futures to dead ends.

On the other hand, many people who once talked and can no longer speak, particularly welcome a speech output device no matter how cumbersome or slow. There are two main problems regarding voice output devices. One is that many physicians are unaware of the existence of these products, (They include two models of the Handi-Voice and the Vois, all distributed by Phonic Ear, Inc., Mill Valley, Calif.; the Express Three made by Prentke-Romich, Shreve, Ohio; the Words Plus device marketed by Words Plus, Sunnyvale,
Calif.; the Dec Talk, a nonportable device marketed by the Digital Equipment Corp., Maynard, Mass.; Vocaids, a product of the Texas Instruments Corp., Dallas, Tex.; and the Form-a-Phrase Possum.)

The other is that the synthetic voice most of these products use is undeniably male. Synthetic female and children's voices are already a reality and are available for some devices, but have yet to be applied to many assistive communication aids because they are technically more difficult to achieve (they take up more memory space on an electronic chip than do male voices) and so are more expensive—though it is thought that advances in chip technology being made by such firms as the Votrex Co. in Troy, Mich., will largely eliminate the cost differential.

Then too, it is not yet clear that a male voice for a child or a woman is necessarily a disadvantage. Some children, for example, apparently like having an adult male voice because it makes them feel important. According to John Eulenberg, of the Artificial Language Laboratory at Michigan State University:

This is an area that really hasn’t been adequately investigated. We are just on the threshold of a period of discovering what the prime factors are in voice output communication aids that are important for personal identification and psychological robustness (10).

PSYCHOLOGICAL ISSUES

While it seems evident that inability to speak, in combination with other disabilities, has profound psychological consequences, this is an area that merits systematic research as it has been little studied to date. For those newly in the ranks of the nonvocal it has been informally observed that, as with any physical handicap, there are sequential stages of denial and isolation, anger, bargaining, depression, and acceptance analogous to the five stages of dying that have been described by Elisabeth Kubler Ross (20). This does not necessarily mean, however, that all those who lose their speech pass through the entire Kubler-Ross-like sequence or want an augmentative communication system even if they do.

At a patient advocacy meeting held in May 1981 at the Northridge Hospital and Medical Center in Northridge, Calif., near Los Angeles, for instance, one young man in his twenties—whose loss of intelligible speech was associated with quadriplegic incurred in a motor vehicle accident over a year earlier—made it clear (through a speech therapist who knew him well enough to decipher his meaning) that he was still too angry at what had befallen him to accept this kind of help. Similarly, a 29-year-old woman with advanced multiple sclerosis that had rendered her speech so ineffective that her meaning had to be guessed at, indicated strongly that she wanted nothing in the way of a technical speech aid.

On the other hand, this kind of response is not universal. At the Clinical Center of the National Institutes of Health, for instance, speech therapist Barbara C. Sonies reports that speech aids for terminal cancer patients unable to talk have made it possible for them to maintain communication with their families. And, this has meant a great deal to those families both when the patients were still alive and when ultimately some died of their disease (44).

Perhaps the most extensive exploration of this topic to date has been made by David Beukelman, speech pathologist in the Department of Rehabilitation Medicine at the University of Washington, in collaboration with Pat Misuda, a speech-language pathologist, and Carole Lossing, an occupational therapist, both at Harbor View Hospital in Seattle (3,5). Their work has been with adult patients in an intensive care unit. Some of these patients have had a chronic degenerative illness, such as ALS, where loss of speech was a direct consequence of the disease process. Others were patients with leukemia and other diagnoses who, in the course of their final hospitalizations, had to be intubated in order to be supported on respirators, which also made speech impossible.

These investigators have found that patients in the terminal stages of an invariably fatal illness do not have the emotional reserves to use an aug-
mentative speech aid unless they have been familiarized with the equipment in advance. Their practice has therefore been to broach the subject with the patient and patient’s family well before speech becomes impossible and to introduce them then to the various devices that might be used to compensate for an inability to speak, should it later occur. The patients then have time to learn to use whichever device is likely to be most appropriate (language board, scanning device, direct selection print output device, synthetic speech output device, etc.). If the patients cannot talk when they are dying, many are then able to communicate with the chosen device until a day or two before the end.

Beukelman and his colleagues suggest, therefore, that hospitals keep banks of augmentative speech aids and rent them just as they rent radios or television sets. In their experience, it is not only the intensive care patients dying of protracted illnesses who can benefit, but also intensive care patients with better prospects for recovery but who are temporarily partially paralyzed, or otherwise immobilized, and unable to speak.

Patients in the second situation often become temporarily psychotic, thus complicating their nursing care. For example, a 23-year-old teacher with Guillain-Barré syndrome who had to be supported on a respirator and a 16-year-old boy whose acute cardiac illness necessitated multiple intravenous lines were both hallucinating, having nightmares, and exhibiting other signs of profound disorientation—largely because they could neither speak nor move. As both had limited hand motion, they were provided with the Canon Communicators previously described. Once shown how to use the devices, these patients became calm and rational within hours. The investigators believe that since emergency rooms often treat patients with similar symptoms, augmentative communication aids may also be useful and cost effective in that setting.

In addition to the type of nonvocal persons just discussed, there are those who have been born with serious physical handicaps including the inability to speak. Most of these are diagnostically classified as having one or another form of cerebral palsy (CP). Many of them have little or no voluntary control of motion.

Older CP children and adults who fit this description have become capable of “speaking” and “writing” because of recent advances in communication aids and in computerized communication aids especially. A few, in fact, have been able to complete high school, continue to college, and may even be able to pursue graduate degrees. Microprocessor equipment has allowed them to prepare full sentences and full texts rather than be restricted to simple yes-no or multiple-choice responses. Certainly this should mean that many will become employable and that the pool of such individuals should grow as school systems open up to them so that the onset of their education is not as long delayed.

Still, not all nonvocal CP persons of comparable intellectual ability have been able to master microprocessor equipment when it has been made available. And presumably even those who have achieved such mastery could have done even better had they become familiar with it earlier. It seems reasonable to ascribe this unevenness in aptitude largely to the limited opportunities for cognitive development many CP children have while they are of preschool age (15).

Physical activity under voluntary muscle control is acknowledged to be the foundation on which language is built. Through such activity, young children learn to distinguish self and non-self, the relationships of objects to each other by size, shape, and weight, and to manipulate and control objects and people in their environment. Nonvocal CP children who cannot draw pull toys, cannot activate windup toys, cannot imitate the sounds and the behavior of what they see around them—in short, who cannot on their own explore themselves or the world—tend to come to these and other concepts late if they come to them at all.

Said another way, the mind and body are partners in the cognitive development of the young child. As Goldenberg observes, there is truth to the old proverb: “I hear and I forget; I see and I remember; I do and I understand” (15). Verbal abstractions, while they can and do result in learn-
ing and autonomy, probably do not produce them as efficiently as does the child’s physical experience with the world.

Are the disabilities of the nonverbal child largely or wholly remediable before he or she reaches the age when children normally begin to undertake academic work? There is no definitive answer to that question at the present. Nonetheless, preliminary results from several research programs suggest that the answer may be yes. Three such programs will be briefly mentioned here.

One of these is the Intervention Project of the University of California, Los Angeles, directed by Laura F. Meyers, an early language development specialist. In a pilot project conducted in 1980 and 1981, Meyers and her colleagues worked with six nonverbal children (four boys and two girls) whose handicaps included mild to severe cerebral palsy, Down’s syndrome, developmental delay, and expressive language problems, and who were 27- to 37-months old when the study began (27,28).

Four different commercially available assistive communication aids were introduced to the children to determine if the devices would increase their use of oral and gestural language and would expand the number of words they used. It was also thought that this strategy might improve the youngsters’ attention spans, scanning skills, and eye-hand coordination, as well as present them with an opportunity to learn first-hand about the principle of cause and effect.

All these expectations were confirmed to a greater extent than had been anticipated. However, gains were greater when the children used the HandiVoice 110, which has a synthetic speech output, than when they worked with the three other devices that offered only visual displays. One child, for example, who had learned only 10 words during a whole year of previous speech therapy imitated and said 25 new words during the very first session he “met” with the HandiVoice. Meyers believes that the critical factors in such improvement were the children’s control of speech output, the reward of hearing what they wanted to say spoken exactly the same way each time, and the fact that the children felt less threatened by a machine than they would have by an adult who wanted them to perform.

A second example of successful training of the nonvocal has been observed using the “Turtle,” a computerized robot toy retailing for about $600, which is manufactured for schools by Terrapin, Inc., in Cambridge, Mass. By linking the toy to a larger computer to augment its “brain power,” E. Paul Goldenberg and his colleagues made it briefly available to severely handicapped nonvocal children, who could make it respond to their commands by operating a switch that was appropriately configured and engineered (15).

Ordinarily, for example, these children were unable to knock over a pile of blocks. But when the turtle was programed with the proper software (easily written in any of several computer languages), they were able to guide the robot across the floor to do exactly that. Moreover, by fitting the turtle with a pen, the children were able to instruct the toy to draw whatever they wished—whether something they had actually seen or a fantasy design—on a piece of paper taped to a table or the floor. The phrase “whatever they wished” is key.

A device such as the robot gives the child a chance to initiate play experiences rather than merely follow the suggestions or requests of others, a situation that fosters autonomy and education readiness. It may also reveal aspects of the child’s potential that would otherwise go unnoticed. The manner in which a child comes up with an idea and generates plans accordingly, as demonstrated by his interactions with this sort of equipment, provides insights into his capabilities that probably could not be obtained by other means.

Although Goldenberg reports that the robot Turtle has been used primarily with older handicapped children and adolescents, robot toys in conjunction with computers could very likely be employed to give many preschool nonvocal CP children an early advantage in developing their cognitive and language skills. While some might object to this arrangement as too costly, the price of microprocessor components is dropping, and the potential savings of reduced special education and institutionalization are appreciable. Estimates of the costs of lifetime institutionalization for a totally disabled person start at $500,000 and go up.
The early development of motor-thinking skills in this particular disabled population was also to have been the focus of a 4-year computer-assisted research project that had been approved for funding by the Department of Education but was suspended because of budgetary constraints before full implementation (52). The multidisciplinary team at the Child Development and Mental Retardation Center at the University of Washington headed by Wesley R. Wilson, had planned to:

1. analyze the motor-thinking elements required by users of communication devices, and educational computer programs, both current and proposed; and
2. develop a set of graduated motor-thinking tasks and corresponding software programs for the Apple II personal computer that the preschool children participating in the project could operate with a single switch.

Wilson and his colleagues had thought that the sequences of games and other play opportunities offered by the software programs would stimulate the intellectual maturation of the handicapped by providing them some of the experiences of their nonhandicapped peers, experiences that they are unable to have on their own. They had planned to use color, graphics, action, and sound as stimuli, feedback, and rewards. While it remains to be seen how effectively computers can substitute for normal sensory-motor activities, it would not be surprising if early familiarization with microprocessor technology accelerated the ordinarily delayed rate of learning of nonvocal children and facilitated their eventual integration into “regular” classrooms.

If so, the planned project, if it is ever implemented could be readily repeated: the more so because the Apple II, retailing at about $2,000 is moderately priced, as personal computers go, and so are most of its necessary accessories. Once designed and tested, it was expected that the special computer software would be relatively inexpensive, too. Since there is now very little educational and recreational software for disabled children below the fifth grade, Wilson and his colleagues believe there would be a sizable market for the programs they had in mind.

TRAINING AND RESEARCH ISSUES RELEVANT TO THE LIMITATION OF CURRENT ASSISTIVE COMMUNICATION AIDS

The mastery of many technologies for handicapped people is fairly straightforward. While it takes some getting used to, for example, walking on crutches holds few mysteries. And once familiar with motorized wheelchairs, users need do little more than turn them on and off and steer them to have them under control.

Not so with assistive communication aids for the severely physically disabled who cannot talk. Because of the complexities of language, because of the limitations of these aids in the face of such complexities, and—most of all—because communication is a dynamic process between sender and receiver, learning to operate these devices is only the beginning of a far more demanding task.

Normal speech proceeds at a rate of about 100 to 200 words per minute, whereas an output of 2 to 10 words per minute is usually the best that can be attained with the present generation of commercially available augmentative communication systems. This disparity requires accommodation by the nonvocal and their audiences alike. As one researcher in the field has put it:

We have concentrated so much on giving individuals an aid that will let them get a word or words out with printed output or high technology voice output that we’ve sometimes completely forgotten that it is not nearly so much one mode of expression or another that makes it hard for these people to communicate as that all modes—whether they are simple language boards or entail the use of highly sophisticated electronics—are slow (52).

In addition, most communication aids have displays, electronic memories, or both that restrict the size of their vocabularies. This means that some things a normal speaker would say directly, must be said in a more round-about way by the users of these aids, while there are other things
that they can only hint at, and still others that they cannot say at all.

The fixed vocabularies characteristic of many of the devices also require compromises with grammar and syntax. The result, at times, is a staccato or "broken English" effect. To be sure, some models can be made to communicate anything. But they do so only if the user makes a laborious effort to string the message together letter-by-letter or phoneme-by-phoneme (a phoneme is a unit of sound such as the "f" sound of "ph" or the "sh" sound of "tion").

Unless given the opportunity to compose the text in advance, nonvocal people are thus at risk of losing their audiences by the time they can communicate. Or the audience may become sufficiently impatient to guess the message—not always correctly—before a person has the chance to fully convey what he or she has in mind.

But it can be as difficult for those in the company of the nonvocal as for the nonvocal themselves to make optimal use of assistive communication aids. This is particularly true in school settings where there are speaking and nonspeaking students in the same class. Teachers tend to be inhibited by children who cannot talk and at a loss as to how to enable them to compete with their orally fluent peers during classroom activities. All too often nonverbal youngsters do little else but watch and listen while they are in school.

Can speaking and nonspeaking children be taught in the same classroom without the latter being merely bystanders? The answer appears to be yes (15). But only if teachers take on the task with adequate preparation and ongoing support.

One of several examples is the Loma Linda University's Medical Center Augmentative Communication Model Program, funded by the Office of Special Education of the Department of Education, which operated in schools for the orthopedically handicapped in two California counties (Riverside and San Bernardino) from September 1979 through August 1982 (11). Through this program, a team of speech-language pathologists went into the schools to show teachers how to assess nonoral children, how to adapt workbooks and other curricular materials for their use, and how to conduct classes so that the nonspeaking pupils as well as the speaking ones could participate.

Thus, the integration of nonspeaking and speaking persons in group situations appears a feasible goal, but not one achieved without effort. Whether it can be accomplished through instructional manuals rather than through the actual presence of specialized and experienced personnel is a question still to be resolved.

In general, while augmentative speech systems are obviously a great deal better than nothing, they are, as Arlene Kraat has pointed out, "only vehicles through which communication and (social) interaction can be achieved" (19). Without training a client in strategies aimed at those objectives, an aid is unlikely to be put to optimal use, even when well matched to a highly motivated user. Developing and refining these strategies is a major research need. So much emphasis has been put on the devices themselves that there is a dearth of information about how to make them actually compensate for an inability to communicate.

More active participation of severely physically handicapped nonvocal people themselves early in the research and development process would probably help in this regard. No matter how well-intentioned, able-bodied professionals simply cannot adequately simulate or assess what such disabled nonspeaking persons actually experience. Keeping in mind that blind engineers helped to produce some of the recent advances for the blind and severely visually impaired, it may be advisable to encourage members of the nonspeaking population to become engineers, linguists, speech-language pathologists, and so forth, if rapid progress is to be made in this field.

It may be, too, that there has been too much stress on those assistive communication devices that have the most sophisticated engineering and electronics. It is not only that they are costly, but also that the technical assistance that is needed to modify and repair them is not always readily available. The author of this study was often told that more research attention should be directed to simple and middle range aids and imaginative
techniques to enhance their effectiveness. It is not that speech-language professionals believe that the effort should be abandoned to develop better high-technology and more sophisticated replacements for speech for the multiply handicapped nonvocal. That there is plenty of room for improvement is obvious. But, at the same time, they believe that much could be accomplished by fuller and more ingenious exploitation of existing aids and technologies. An example of one problem and one uncomplicated solution to it may make this issue clearer (47).

The problem is that a small child for whom the best way to point is with a regular headstick often cannot use one unless it is so short that it will point only to things at very close range and within a very limited arc. Small lightweight optical lightsticks or lightpens fastened to the head are one answer to this frequently encountered problem. Because their beams goon for a considerable distance before they fade out, these devices can serve as pointers, allowing users to indicate an object whether it is right in front of them or at the other end of the room.

More than mere convenience can ride on this kind of flexibility. A severely physically disabled nonvocal toddler can be asked at supper whether he wants, say, a bite of hamburger or a bite of baked potato next, and using the nightstick, he can respond no matter where on the plate those items are. The choice this permits him in controlling his environment—despite the fact that he may have to be fed by someone else—fosters a sense of independence that is an important part of nourishing his self-esteem.

Whatever the age of the assistive communication aid client, strategic training considerations include the following:

- assessing the match between the aid and the potential user’s motivations and abilities;
- considering the communication content of the aid. Persons with some kind of brain injury communicate more effectively with symbolic or picture “languages” than with traditional alphabetic systems. Whether symbolic, pictorial, or orthographic, vocabularies need to be suited to the user;
- preparing the user, who has an acquired speech loss, to accept the constraints on his expression that the aid imposes and to compensate for them by: 1) preparing texts in advance when possible, 2) saying things more concisely, and 3) expecting prediction and anticipation from listeners;
- teaching the nonspeaking child or adult who has never acquired speech to use language by building on his earlier experience and longstanding patterns of behavior, emphasizing particularly what to talk about and starting and maintaining conversations;
- stressing flexibility by encouraging users to switch communication tactics when one proves ineffective; and
- making social interaction a higher priority than perfection of grammar, syntax, or vocabulary (32).

Last, but not least, training ideally should address the environment as well as the user. In other words, it should also concern itself with the speaking community. Speaking partners of nonvocal persons can often learn techniques that make communication more efficient and effective. As already mentioned, such cooperation is crucial in schools, but is also important in employment settings and for families, attendants, and friends.

**THE COMPATIBILITY OF SYSTEM COMPONENTS**

The effectiveness of commercially available assistive communication aids is not only a factor of how well the client has been fitted for an augmentative speech system, but also the construction, operation, and design of the equipment itself. However well a device works for a given user,
it is often hard to identify which of its characteristics have contributed to the result unless baseline and followup data from field studies are available.

Efforts to collect such data are only just beginning. The most ambitious field study to date is in progress at the Assistive Devices Center of the School of Engineering at California State University, Sacramento, under the direction of Albert M. Cook. The Center follows clients at 3-, 6-, and 12-month intervals and has produced reports (published individually) on nine assistive communication aids as a result. Some of the findings have been incorporated into product design modifications by manufacturers (7). More of such studies are desirable both for the information of nonvocal persons and for that of third-party payers, who are understandably in need of persuasive evidence that investment in these technologies is worthwhile.

A related problem is the frequent lack of compatibility among the various electronic communication systems and environmental control aids with interfacing switches and accessories. Van derheiden and his colleagues point out that “as might be expected, nearly every researcher and manufacturer chose a slightly different connector, pin-out, voltage convention or format . . . (with the end result often being) that the handicapped individual is fitted with an aid, interface, and accessories which do not fit together well” (45).

To remedy the situation, the International Standard Interconnection Task Force was organized in December 1980. This task force, composed of clinicians, manufacturers, and researchers from the United States, Canada, and Europe, has the following objectives:

- develop a common technical format for aids and interfaces;
- develop a common connector or connectors for those components; and
- develop a simple, readily understood naming format that will enable people not technically trained to mix and match aids, interface, and accessories to meet the needs of handicapped individuals.

The task force has its headquarters at the Trace Research and Development Center for the Severely Communicatively Handicapped at the University of Wisconsin-Madison. It is funded by the National Science Foundation.