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Information and Funding for the Speech-Impaired

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INFORMATION RESOURCES

Ready access to information about appropriate aids and techniques is vital if the needs of the handicapped population are to be met. How well are severely physically disabled nonvocal persons served in this regard? The author of this study has found that, although major steps have been taken to obtain information on this population—information which was almost wholly lacking as recently as the mid-1970's—incomplete and fragmented data collection and dissemination efforts continue to be a major problem.

Some information resources on the disabled nonvocal include the following:

1. *ABLEDATA*.—This is a computer data base, funded by the National Institute of Handicapped Research and headquarters at the National Rehabilitation Information Center at Catholic University in Washington, D.C. Its capsulized contents are made available to interested parties through information brokers whose names the Center gives to prospective clients (anyone who needs the information) on request. The system has been plagued by poor funding, a situation reflected in its print-outs on communication aids. While they do provide descriptions, price, and manufacturer information regarding many systems, not all aids are included in its listings and reports on those that are included may not always be entirely up to date.
2. *The Non-Vocal Communication Resource Book*.—University Park Press, Baltimore, \$15.95; yearly updates for this looseleaf binder volume are \$7.50. Compiled by the Trace Research and Development Center for the Severely Communicatively Handicapped at the University of Wisconsin-Madison, this illustrated volume—funded in part by the Federal Government and in part by the United Cerebral Palsy Research and Educa-

tion Foundation in New York—is the most comprehensive reference in the field. It offers speech professionals, educators, parents, and administrators concise information about: 1) commercially available devices and their prices; 2) some communication systems under development in research settings; 3) devices that are not commercially available, but nonetheless are readily duplicated by, say engineers affiliated with the special education unit of a school district, perhaps through a public-spirited church or civic group; 4) an interface switch profile and annotated list of commercial switches; and 5) a bibliography. The book, however, does not pretend to be all inclusive and is really best described as a very good catalog. Thus, for example, it provides little or no information about the strengths and shortcomings of given devices. Nor does it discuss the extent to which any device has been tested in the field, the clients involved, and the results obtained.

3. *Trace Center International Software Registry: Programs for Hand-capped Individuals*.—Issued in January 1982, this registry, whose initial cost is \$12 and for which there will be periodic addenda, should serve as a clearinghouse for information on computer-assisted educational and recreational materials. The registry lists descriptions of the programs, manuals for the programs, computer requirements for the programs, etc. The reader is also able to learn from the registry the prices of the programs and from whom he may order them. Home hobbyists and others who have developed programs, but who do not have the facilities for manufacturing them, are invited to submit entries. The only proviso is that they permit the Trace Center to duplicate and

disseminate their products at cost. As in the *Non-Vocal Communication Resource Book*, no attempt will be made in this registry to evaluate materials described.

4. *Communication Outlook*.—This quarterly newsletter, published by the Artificial Language Laboratory at Michigan State University jointly with the Trace Center at the University of Wisconsin at Madison, the official publication of the International Society for Augmentative and Alternative Communication. It “is addressed to the community of individuals interested in the application of technology to the needs of persons who experience communication handicaps due to neurological or neuromuscular conditions.” The newsletter is an invaluable source of information, providing its readers with news about the delivery of clients’ services and about individual users, as well as about the communication aids themselves.

Communication Outlook accepts advertising and has about 2,000 subscribers who pay \$12 a year to receive it. In addition, it is distributed to several thousand other people through a variety of channels. As the

first international journal to have brought together professionals in disciplines that participate in the communication aids field and their clients, it has also published a comprehensive bibliography dealing with the many issues involved. The bibliography is available in printed form and also as an updatable and queryable data base on computer diskettes, containing a program that allows users to selectively generate subsets of the bibliography that particularly meets their needs. The bibliography can also be accessed with Radio Shack TRS 8-III and Apple II computers. Annual updating is planned.

5. *Features of Commercially Available Communication Aids*.—A wall-chart listing of both portable and nonportable aids. It is prepared by Arlene Kraat of the Queens College (New York) Speech and Hearing Center. It covers communication output factors, selection factors, portability, and distribution sources. It is available from Prentke-Romich Co.; 8769 Township Rd., 513; Shreve, Ohio 44676.

OTHER SOURCES OF INFORMATION

While professional journals like those of the American-Speech-Language-Hearing Association (ASHA) (which has a circulation of about 40,000) and the Journal of the Institute of Electrical and Electronics Engineers (which has a worldwide circulation of about 50,000), do carry relevant material, it is on a sporadic basis. Besides, there is no guarantee that these journals will be read by certain audiences—nurses and physicians, for example—who need to be informed about the subject.

Much the same is true of a wide spectrum of other publications that are intended as much for the laity as for professionals. *Echo On*, a newsletter published by Phonic Ear, Inc., in Mill Valley, Calif., is an example of such a publication. Its primary purpose is to publicize the use of the synthetic voice products the company markets for the nonvocal (i.e., two models of the HandiVoice and

the Vois). It also occasionally covers topics of related interest, such as assessment and training. But, as is typical of a newsletter, its articles are necessarily brief and anecdotal. While they do provide readers with ideas, their usefulness to professionals and their clients is still limited.

Funding constraints having adversely affected both periodicals and the compilation of catalogs, registries, and bibliographies in this field, and also the publication of conference proceedings. For example, the proceedings of a conference on voice output communication aids that was held at the Center for Independent Living in Palo Alto, Calif., in spring 1980 under a National Science Foundation award to Telesensory Systems, Inc., of Palo Alto have yet to be published. Because the award allotted no funds to organize or disseminate the products of the conference, these materials have been put into storage and are not available,

although a few of the papers can be obtained with effort from individual contributors.

In time some of the missing information may be supplied by alternative means under entirely different kinds of auspices.

A prime example is CONFER, a computerized teleconferencing system, designed by Robert Parries at the University of Michigan, Ann Arbor and organized by Shirley McNaughton at the Blissymbolics Institute in Toronto during 1983 (26). Using a computer at Wayne State University in Detroit, the system allows communication aids professionals and anyone—vocal or nonvocal—with an interest in the field who has local access to a computer and model telephone device to have the same kind of interaction they would have at a conference. Thus, one can send “items” via the Wayne State Computer and telephone to the entire group of people who belong to CONFER or direct messages only to particular members of CONFER. There is an initial charge of \$50 for this service and any additional charges are made as more than \$50 worth of service is used. Billing is handled by the Blissymbolics Institute.

Similarly, in 1981, the National Association of State Directors of Special Education (abbreviated as NASDSE and headquartered in Washington, D. C.) opened Special Net, a 24-hour-a-day, 7-day-a-week, telephone-access computerized news

service, that has a number of “bulletin boards, ” and serves 22 States so far.

At present, the \$200-a-year service heavily emphasizes legislative developments and other policy issues in its bulletins to administrators in the special education field. However, it is hoped that, as additional subscribers are attracted to the service, the service’s scope will expand to provide more bulletins focusing on matters of immediate practical action for special education teachers and their students. NASDSE may eventually start a second computerized network to deal specifically with rehabilitation topics. If so, membership will likely extend to any organization with relevant concerns and perhaps even to individual professionals (43).

At least one organization concerned with the needs of individual handicapped persons has already tied into the existing NASDSE network. The California Repository for the Handicapped located in Sacramento has a “bulletin board” that runs want ads on devices needed and devices available, whether new or secondhand. At present its coverage is pretty much confined to the blind portion of the handicapped community in northern California. But there seems little reason why other “bulletin boards” could not be organized regionally to serve a wider spectrum of needs.

FUNDING ISSUES

On May 3, 1981, a Chicago jury awarded 46-year-old Eileen Tannebaum \$6.5 million and her husband, Louis, an additional \$2.5 million for injuries she incurred during surgery that left her a quadriplegic and unable to talk (37). Some of the \$8 million for which the case was ultimately settled was used to provide Mrs. Tannebaum a cus-

tomized communication system, designed by the Artificial Language Laboratory at Michigan State University (10). Although larger than most, this is one of several medical malpractice and personal injury settlements the author of this study identified that has been used to underwrite customized assistive communication aids technologies.

However, the disabilities of most severely disabled nonvocal persons are not the result of medical malpractice, and so these people do not have access to this resource. Nor do they usually have extensive personal financial means. They and their families therefore heavily depend on traditional third-party payers as sources of funds for communication aids. The following federally assisted and private programs are those pertinent to consider in this regard.

Medicare

It might be expected that both persons who are over 65 and those who are chronically disabled would be eligible for payment under terms of the law. In practice, Medicare has funded communication devices for nonvocal individuals also unable to write only for use in a hospital or skilled nursing facility to communicate with staff—in other words only under Part A of the Medicare law. In no instance has the Social Security Administration's Health Care Financing Administration authorized purchase of such devices under Part B of the law, which would permit Medicare beneficiaries to make these prostheses part of their everyday lives (10).

Medicaid

Though this program for the indigent and medically needy is through Federal-State partnership, decisions are made at the level of State or county by State or county personnel. Medicaid has covered communication aids in several States, including California, Oregon, Washington, Wisconsin, Illinois, Colorado, New Jersey, Massachusetts, and New York. In some States, however, there has been no such coverage, and even in those States where there has been coverage, it has not necessarily been in all locales. Approval or disapproval of reimbursement is largely based on the decisionmaker's personal interpretation of guidelines, if any, that maybe available. Any funding that is made often takes months or years to obtain. Clients often face many refusals and must go through repeated hearing processes to have a chance to succeed (38).

Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)

Coverage for assistive communication devices is specifically excluded from the so-called basic program that pays for medically necessary services and supplies for the dependents of active duty or retired military personnel. They also "generally do not qualify" for cost-sharing under the CHAMPUS program for the handicapped that provides financial assistance to active duty members for the care, training, and rehabilitation of a spouse or child who is seriously physically handicapped or moderately or severely mentally retarded. Some exceptions have been made to provide basic communication necessary to accomplish training or teaching of a seriously handicapped individual (13).

Crippled Children's Services

Like those of Medicaid, these services are administered under a Federal-State partnership, and like that of Medicaid, funding by locale (38). Thus, payment has been provided in some States, but not others, and in parts of some States, but not all parts. Again, long delays between requests for funding and the actual provision of it often cause postponements of months to a year or more. Moreover, some crippled children's agencies will pay indefinitely for traditional speech therapy, but not for augmentative aids, even though a client fails to make noticeable progress in traditional therapy (33).

Social Security Insurance and Social Security Disability Insurance

These programs provide direct financial assistance to eligible disabled individuals. Insofar as the author of this study could determine, neither has allowed reimbursement for communication aids.

Public Law 94=142—Education for All Handicapped Children Act of 1975

Under this act, State funds for the education of handicapped children and related services are

supplemented by Federal grant, providing that school districts meet certain requirements. Funding for assistive communication devices varies by State and by school district. Funding has been obtained either on the basis of a child's individual education plan (IEP) as required by the law, or from the local education agency, without reference to the IEP. However, the emphasis in the law is on "specially designed instruction," so that it is not entirely clear whether payment is to be made for devices that make that instruction possible. Thus, some school districts and local education agencies have funded assistive devices and others have refused to do so. When funded under Public Law 94-142, equipment is only for classroom and homework use; it is generally not available to beneficiaries during vacations. Public Law 89-313 is similar to Public Law 94-142 except that the beneficiaries it concerns are enrolled in State-supported or State-operated schools.

Vocational Rehabilitation

Like Medicaid, vocational rehabilitation is another of the federally assisted, but State-administered programs. The emphasis in its funding is on whether the requested device will enhance an individual's employability. Programs in California, New York, Massachusetts, and Oregon are known to have reimbursed. However, there may well be States that have denied funding, and if the severely handicapped client in question has no relatively near-term prospects of employment, denial is usually certain.

Veterans Administration

The Veterans Administration will fund any communication device prescribed for a person who has a "service connected disability." Should the individual's inability to speak not be "service connected," funding for evaluation may be obtained through the Administration's Prosthetics Evaluation Centers. In such cases payment for the actual purchase of equipment is sometimes provided and sometimes not.

Private Health Insurance Sources

Private health insurance sources include the various Blue Cross-Blue Shield plans and the commercial carriers of health and accident insurance. Their funding of assistive communication devices in general depends on the terms of the policy and the nature of the disability. A growing number of companies are beginning to offer reimbursement for such devices, particularly if the severely physically disabled nonvocal person has major medical coverage. But some companies (both the "Blues" and commercial carriers) do so only on a case-by-case basis, while others do so under some of their contracts but not others, and still others do not do so at all. The various field offices of some companies seem to have considerable latitude in interpreting policy contracts, so that even a carrier whose overall policy is to provide payment may not do so in all locales.

Private Disability Insurance

These policies are written by commercial carriers. Chances of their covering assistive communications equipment are good if the aid in question will permit a person to work or will reduce the costs of his care; otherwise, they are not.

Workers' Compensation

Workers' compensation provisions vary by State. In most States persons eligible for coverage who need assistive communication devices *are* able to obtain funding if the equipment: 1) seems likely to permit them to return to work, or 2) results in less need for attendant care. The second is a consideration only in workers' compensation cases because it involves a potential cost saving to the insurer. Other types of health or disability insurance generally do not pay for the hire of attendants.

Unions and Employers

Both unions and employers may consider funding communication equipment if evidence is furnished that such equipment will improve the in-

dividual's ability to function on the job. Unions have purchased assistive communication devices in California and New York (39). In principle at least, employers receiving Federal financial assistance may be required to provide a communication device as a "job accommodation" or "job modification."

Service Clubs

Groups like the Lions, Kiwanis, Moose, Ser-toma, and Rotary clubs have an interest in serving the community and have specifically shown a concern for the handicapped. However, their funding of assistive communication devices is only done case by case.

Voluntary Health Agencies

The Muscular Dystrophy Association in New York City has a loan bank of communication devices that is available to individuals who have a neurological or neuromuscular disorder that results in loss of speech. However, in 1981, the asso-

ciation decided that no device costing more than \$100 would be added to the bank. It will keep those more sophisticated and more costly devices it already has, but in the future will purchase only simpler aids such as language boards. Insofar as the author of this study could determine, this organization is one of the only two voluntary health agencies that has gone even this far (48). The National ALS Foundation manufactures, markets, and services a communication aid called the ETRAN Communicator (which helps the user to communicate with eye movements and sells for about \$20).

No voluntary health agency identified by this case study includes assistive communication devices in its authorized programs of service. Some do offer information to clients and their clinicians on possible sources of funding and regarding what arguments to make on behalf of applications (39). Occasionally, a voluntary health organization has paid the balance of the bill for a communication aid when, as is usually the case, a traditional third-party payer will not pay the full amount and no other source of funding can be found (6).

DISCUSSION OF FUNDING ISSUES

There is an old axiom in medicine that when there are many different treatments for the same disorder the likelihood is that none of them works very well. From the perspective of the severely physically disabled nonvocal person, the same principle applies in finding a payment mechanism for the assistive communication device that will meet his needs: the many potential sources for funding disguise the reality that reimbursement can be very difficult and sometimes impossible to obtain. Because no single agency in government or the private sector is specifically authorized to assist this population, all tend to say it is not their responsibility and try to shift that responsibility elsewhere.

Little statistical information has been collected on the number of people who have obtained coverage or been denied coverage for these devices by third-party payers. Obtaining an approximately accurate count is, in fact, a major research need.

Nonetheless, it is evident that funding disapprovals are a major barrier to the rehabilitation of the multiply physically handicapped nonspeaking population and to manufacturers' development of assistive communication devices. (More will be said about this in the section, *The Industry Perspective*.) It is also obvious that third-party payers' philosophies are frequently: 1) inconsistent or arbitrary, 2) not necessarily based on rational premises, or 3) both.

In its administration of Medicare, for instance, the Health Care Financing Administration (HCFA), which sets payment policy for the program, does not cover assistive communication devices of the types this case study discusses for beneficiaries who could be expected to use them outside a hospital or skilled nursing home. HCFA's reason for the refusal is that this equipment "does not replace an internal body organ or the function thereof" (6). The paradox is that HCFA routinely approves

payments for electrolarynxes for cancer patients whose loss of speech is due to surgical removal of the natural voice box.

Like that of the assistive aids in question, the purpose of these hand-held devices is to enable patients to communicate for socialization, self-care, health care, and, when possible, employment. Thus, the significant difference between the two classes of prostheses—one for patients with cancer of the larynx, the other for patients with a variety of other diagnoses—is obscure because both are means to the same ends.

The word “prosthesis” is, in fact, a term that third-party payers have referred to in refusing to reimburse the purchase of assistive communication aids. This rationale has been that the Food and Drug Administration’s (FDA) Bureau of Medical Devices does not define communication aids as prostheses—as artificial devices to replace a missing part of the body. But again, the agency does so define electrolarynxes, and again, whether by Medicare or some other third-party payers, denials of requests for the funding of electrolarynxes are rare.

When FDA was asked why it considers electrolarynxes to be prostheses and assistive communication aids not, the Chief of the Neurological Devices Branch in FDA’s Bureau of Medical Devices replied that the term had been avoided not because the agency truly believes that the second sort of technology is not prosthetic, but rather to avoid regulating it (31). He said that such regulation had been judged unnecessary from the standpoint of safety, and that it would impose a needless burden on a fledging industry. Ironically, that FDA decision would seem to have contributed itself to burdening the industry, as denials for reimbursement based on this lack of definition have caused manufacturers and distributors to lose potential sales.

Another term that is often mentioned in denying reimbursement is “medical necessity.” In contrast to electrolarynxes and certain other forms of durable medical equipment (wheelchairs, for instance), assistive communication devices are often perceived by third-party payers as only “patient conveniences” and are therefore ruled out for coverage. As most of the target population

are essentially immobile and thus helpless in an emergency if they cannot communicate, the validity of this argument seems dubious.

The impression of the author of this study is that many third-party payers will present almost any reason to deny a request for the purchase of an assistive communication device. The author was repeatedly told by manufacturers, by professionals in this field, and by affected individuals and their families that third-party payers in the health field often take the stance that this equipment should be paid for by programs whose primary purpose is educational or vocational whereas programs with those missions tend to tell them that the responsibility properly belongs to organizations that underwrite health care. Some third-party payers, in fact, have confided to providers that they fear there may be so many non-vocal persons in the population that to provide all of them with remediation would be to break the bank.

Clearly, one reason for the problem of funding is that at a time of fiscal constraint there is an understandable emphasis on holding down costs, and expenditures for equipment are often slashed from budgets first. Another is that the behavior of personnel in the field office of third-party payers—particularly those in the private sector—may not represent the attitudes of the home office management. The varied fates that await funding applications for assistive communication devices seem to reflect different values in different locales, at least where traditional third-party health payers other than Medicare (i.e., Blue Cross-Blue Shield, commercial health and accident plans, Medicaid, Crippled Children’s Services, etc.) are concerned. There was ample anecdotal evidence of this in interviews the author conducted in Massachusetts, Michigan, Wisconsin, and the State of Washington.

This evidence was supported by the preliminary results of a study being conducted under a grant from the National Institute of Handicapped Research (an agency of the Department of Education) by David Beukelman of the Department of Rehabilitation Medicine at the University of Washington (4).

Beukelman is in the process of looking at the outcomes of about 200 applications for the funding of communication aids that have been made to traditional third-party payers. He is collecting his data from hospitals, nursing homes, device manufacturers, and individual speech and occupational therapists in private practice and school districts, and has arranged his collection system so as to protect client confidentiality and to prevent any claim filed on behalf of a client being counted twice. While his study sample is being drawn exclusively from Washington, Oregon, California, Alaska, and Idaho—with emphasis on the first of those States—it is a sample large enough so that it maybe representative of trends in the Nation as a whole.

With the exception of Medicare, Beukelman has found that no third-party payer has a standard payment policy for these devices; rather, a diversity of attitudes is found among funding agencies, according to locale. In the State of Washington, for example, his data indicate that it has generally been easier to obtain communication aid payments for adults—particularly those aged 20 to 40—whose loss of speech is acquired than for children or adults whose inability to speak is traceable to a condition present from birth. In this case, potential prospects for employment in the near future appear to take precedence over the eventual employability and generally greater life expectancies of nonspeaking persons who are not yet old enough to leave school. On the other hand, the situation in California seems to be somewhat reversed.

Beukelman reports that his data from that State are too sparse to be reliably indicative of funding trends. But Montgomery and Hansen have found that California third-party payers, while generally unwilling to fund applications made on the behalf of young children, tend to approve those submitted for clients aged 15 to 25 who are still in school—presumably because they are on the verge of entering the labor market and can have little hope of being employed without some means to communicate.

Less surprising, perhaps, is that the cost of the communication device or communication system is, according to Beukelman's data, a major fac-

tor in determining whether a funding application is approved. Still, Beukelman has found that acceptance or rejection of a claim is not wholly a matter of equipment expense. Instead, success often depends on who is doing the asking and how strongly and persistently.

A request made on behalf of the patient by a physician, for instance, is often more readily honored by a third-party payer than one made by a speech or occupational therapist, even though these allied health professionals are generally more knowledgeable in the area than are most M. D.'s. (Although, the habit many physicians have of merely scribbling the name of the device requested on a prescription blank appears to be associated with a high rate of rejection for reimbursement.)

Similarly, supporting letters funding request to third-party payers that emanate from health professionals based at hospitals with established reputations for dealing with the target patient population are, for the most part, according to Beukelman's preliminary findings, taken more seriously than those from their counterparts primarily affiliated with nursing homes or convalescent facilities.

Other considerations in funding include the fact that applications have a greater likelihood of success when they are accompanied by supporting letters offering persuasive evidence that the device will enable the patient to function more independently and at less cost to all concerned. * When the claim submitted is for something with which they are generally unfamiliar, the processing costs rise accordingly since more time has to be spent in validating its legitimacy. Thus, rather than spend time and money, it is often more cost effective from the insurer's point of view to withhold approval of the request.

As all this suggests that assistive communication devices and communication systems are at a disadvantage in the reimbursement process because unlike the electrolarynx and certain other forms of medical equipment—they are recently introduced technologies. Not all health care tech-

* Also, third-party payers are understandably concerned about the cost of processing claims.

nologies of recent origin, however, are similarly disadvantaged. Thus, the explanation cannot lie in novelty alone. What other factors are at work?

One of these, surely, is that these technologies are not only new, but also very different from predecessor technologies in terms of the patient population they serve. Third-party payers are far more accustomed to reimbursing claims submitted in connection with acute episodic bouts of illness (and with illness requiring surgery in particular) than they are to honoring those for remediating a condition in a person who is disabled, but not necessarily sick. The distinction is pertinent because it means that providers cannot easily submit bills for rehabilitation services and technologies—as they sometimes can with technologies associated with acute illness—in the guise of their being for practices and equipment traditionally reimbursed.

Probably more important is that assistive communication devices and systems are unfamiliar or unknown to most physicians. Rehabilitation medicine is, in general, a neglected topic both in undergraduate and graduate medical education where the thrust is more towards specialties and subspecialties dealing with the application of discrete technologies to particular organ systems than toward improving overall patient functioning. Very little course time is devoted to multiple physical disabilities and to multiple physical disabilities in conjunction with speech impairment, even for recently trained pediatricians and neurologists whose educational philosophies acknowledge the importance of the development of language and speech (12).

Moreover, physicians in the field of rehabilitation medicine, and thus likely to be aware of augmentative communication technology, are relatively few and not especially prestigious in the eyes of practitioners in more mainstream specialties such as surgery, internal medicine, family practice, pediatrics, etc. Rehabilitation specialists thus do not have a great deal of influence on their colleagues in other fields.

These factors together have also conspired to give assistive communication technology little visibility in the medical literature. The publications with the widest physician readership such

as *The Journal of the American Medical Association*, *The New England Journal of Medicine*, and others, rarely, if ever, deal with this subject matter. Nor does their advertising. Thus, there is almost nothing in the professional environment of most physicians that would bring their attention to these issues. Since they have also received little attention from the lay media, there is little impetus for change from that direction either.

The reimbursement of assistive communication devices and systems is further complicated by the role, somewhat down the health care hierarchy, of speech-language pathologists. Though they have knowledge and skills that are of special value to communicatively impaired people, they have struggled for recognition as professionals and against the threat of their functions being usurped by physicians.

Many physicians remain suspicious of speech-language pathologists if for no other reason than that they are generally trained by the faculties of schools of the arts and sciences, rather than by the faculties of medical schools. From the perspective of the physician, this makes them appear less rigorously trained and, therefore, less than full health professionals—an attitude that is reinforced by the insistence of third-party payers that only claims based on physician prescriptions will be considered for reimbursement.

Moreover, although the American Speech-Language Hearing Association (ASHA) never took such a position officially, some practitioners in the field were long influenced by the dogma that all nonvocal clients (except those whose loss of speech ensued from removal of the larynx for cancer) should learn to speak unassisted and that, accordingly, assistive communication aids were a passing fad. This, too, has tended to discourage coverage of these technologies by third-party payers (51).

There are clear signs that this philosophy is becoming outmoded. The August 1981 issue of the ASHA journal, for instance, was almost wholly devoted to articles that portrayed assistive communication aids in a favorable light. And ASHA had planned to hold a conference on this subject in 1982, but was unable to get the requisite funding from the various Federal agencies to which it applied for support.

Nonetheless, just as medical school curricula neglect this subject matter at both the undergraduate and graduate levels, this has also been true of many speech-language pathology curricula. Again, there are some indications of change. A recent ASHA survey of college and university speech-language pathology programs found that almost 95 percent of them offer at least some course work in augmentative communication and that half of them offer at least one complete course (8). Still, there are practicing speech-language pathologists who got their training before these curriculum changes were introduced and thus are almost entirely unfamiliar with assistive communication technologies. And though familiarization with them may be available in most current speech-language pathology training programs the relevant courses are not always required. Moreover, even if required, these courses may devote only superficial attention to how these technologies are best applied.

In fact, occupational therapists have historically often been more receptive to assistive communication aids than many speech-language pathologists. This lack of receptiveness among speech-language

pathologists can have particularly unfortunate consequences for multiply physically disabled children whose lack of speech is congenital. This inability to communicate is often first professionally addressed when they enter school where special education programs more often rely on speech clinicians than on occupational therapists, who, instead, tend to be affiliated with medical centers, or nursing and convalescent facilities.

When speech clinicians who have not been specifically trained to serve this population are, in effect, the providers, it is not only their possible ambivalence towards the technology that weakens its likelihood of reimbursement. It is also that third-party payers are aware that such clinicians may or may not be sufficiently competent to prescribe or to counsel a prescribing physician. Again, this is a disincentive to reimbursement. Administrators of payment programs who have reason to question the competence of the prescriber rarely hesitate to deny requests for funding the prescription, or at least to subject such requests to a process of scrutiny that can delay implementation for months or years.

SUMMARY

In principle, the third-party payment system exists to serve the needs of the handicapped, as well as those of the acutely ill. In reality, it is so fragmented that many of its intended beneficiaries fall into the cracks. A natural tendency to deny or delay reimbursement for assistive communication devices because of their unfamiliarity is intensified by the reluctance or inability of physicians and

relevant allied health professionals to make a persuasive case for them. The failure of such professionals to make this case has fueled arbitrary, inflexible, and often inconsistent behavior on the part of third-party payers and deters the dissemination of assistive communication technology and its appropriate utilization.

THE INDUSTRY PERSPECTIVE

Advances in electronics in combination with legislation enacted on behalf of handicapped persons encouraged several firms to enter the assistive communicative aids market by commercializing products developed in research, during the mid to late 1970's. There appeared to be a good fit between the needs of a user population and those of industry. It was, therefore, to be expected that

as the companies in question prospered they would plough some profit back into further research and development.

In fact, the expected fit has hardly materialized. The top seller in the field is the Canon Communicator, a portable tape typewriter marketed by Telesensory Systems, Inc., of Palo Alto, Calif.,

which is small enough to be easily carried. Yet Telesensory Systems has been able to sell only about 1,500 of these units since it introduced them in 1977, and its continuing to market them has been at the expense of diminished profits from its other product lines. Meanwhile, the runner-up device—the HandiVoice marketed by Phonic Ear, Inc., in Mill Valley, Calif.—has done only half as well in approximately the same length of time. Although no precise figures are available for the market as a whole, since they are proprietary information, it is evident that sales volumes for the entire industry have been low.

A corollary is that very few of the estimated 75,000 to 1.5 million severely disabled nonvocal persons have had access to these devices, because, at \$500 or more each, the devices are beyond most persons' means. An educated guess is that no more than 3,500 to 6,000 nonvocal severely disabled persons have been served by such equipment to date.

The reluctance of third-party payers to reimburse for these technologies is the main reason they are little used. The reluctance has, if anything, grown as public sector programs have had less money to spend and have tended to give expenditures for capital equipment the lowest priority—despite the likelihood that the investment would often permit less client dependency and, therefore, lower taxpayer expense.

In addition, even those applications that have ultimately been approved for funding have often generated lower than expected revenues for manufacturers and distributors because:

1. the firms have had to devote time and effort to helping educators, health care providers, and their clients try to get third-party payers to agree to the purchase;
2. there have often been delays of months to a year or more in reimbursement, and
3. some third-party payers—not only Medicaid agencies—have made it their policy to base reimbursement on only a partial percentage (typically 85 percent) of the listed retail cost of the device.

In many States, these agencies have also made it a condition of reimbursement that the manufac-

turer or distributor not seek additional money from the person who is to receive the equipment or from his immediate family. At least two firms have therefore stopped doing business with agencies that impose these demands.

Faced with such economic disincentives, private industry involvement in augmentative communication for the severely disabled nonvocal is necessarily restricted. Thus, this industry may well have to put reducing costs ahead of innovation and product betterment if it is to survive at all. The microprocessor and the semiconductor have made state-of-the-art electronic devices for the disabled ready for commercialization. But in the absence of the volume of business anticipated from third-party payments, these technologies are hostages to risk factors that some quarters in industry feel powerless to overcome.

To be sure, this is not always the case. In the fall of 1982, for instance, the Texas Instruments Corp. introduced its Vocaid, which is now being sold to school districts, hospitals, nursing homes, and rehabilitation centers. This is a digitalized artificial voice output communication aid designed primarily for people with temporary or short-term speech loss and sufficient motor control to use its touch-sensitive surface which is divided into 36 squares and comes with a set of overlays that give it a fairly extensive, but not unlimited, repertoire of words and phrases.

However, the device—which sells for about \$150—is a spinoff from an earlier Texas Instruments product (the Touch and Tell educational toy for young children). Thus, it might well have never been modified and commercialized had Texas Instruments not already had a running start on this technology.

Similarly, the Apple Computer Corp. has published a resource guide on using computers for the disabled and publicized applications of its products to the communications needs of nonvocal severely physically disabled persons in its magazine (1,18,22). And the Radio Shack Division of the Tandy Corp. has helped to underwrite a contest, sponsored by the National Science Foundation, to make personal computers more accessible and more useful to people with a variety of handicaps.

But neither company has taken steps to go beyond such honest broker roles, apparently because the characteristics of the potential market do not merit industry's direct entry into producing or distributing products specially designed to compensate for communication disabilities.

Meanwhile, those companies that have marketed specialized assistive communication aids have been disadvantaged by the disincentives to third-party payment already discussed. Other discouraging factors from the perspective of industry include the following (36,51):

- High research and development costs for new technical aids or for substantive redesign or modification of existing aids. Such research and development is expensive, because human factor studies are required to adapt equipment operation to the physical limitations of the handicapped, about which little is known to begin with.
- Few nonvocal severely handicapped persons with sufficient education and technical expertise to participate in research and development as professionals and so help industry avoid costly design mistakes.
- Restrictions in some government programs supporting rehabilitation research that make profitmaking firms ineligible for grants and contracts. Some manufacturers complain that this results in developing prototypes in university settings in a manner that fails to take production factors into account, thus making the transfer to commercialization needlessly costly and difficult. However, the Small Business Innovative Research Program that has come into being during the Reagan administration may go a long way towards solving this problem. Already, for example, the National Institutes of Health have awarded grants and contracts, *16* relevant to assistive communications, to small businesses under this program.
- Very high marketing costs associated with reaching the small, diverse, and geographically dispersed population of prospective assistive communication aids users, a problem compounded because speech professionals, special education professionals, physi-

cians, and others involved directly in health care delivery often have little or no knowledge of or training in this field.

- A population of prospective users that is hard to identify because its members are usually classified according to another disabling condition, the manifestations of which sometimes do and sometimes do not include an inability to talk. For example, only a minority of persons with cerebral palsy are totally nonvocal. Similarly, not all those with traumatic head injuries lose their speech either temporarily or permanently.
- A population of prospective users that does not come with a-readymade advocacy and service delivery infrastructure built around a shared functional inability to talk. This population contrasts with that of the blind who—despite the fact that they are blind because of a variety of pathologies—have been able to make their common inability to see the central issue in persuading both public and private sectors to help meet their needs. (Of the disabled, note that only the legally blind are automatically entitled to a Federal income tax exemption. Similarly, there is a registry of all agencies and organizations that serve blind people in the United States, but no such registry for those who are unable, for whatever reason, to talk.)

Furthermore, the many groups organized around given diseases or diagnoses (e.g., multiple sclerosis, amyotrophic lateral sclerosis, cerebral palsy, etc.) tend to share very little information about the communication disabilities found in their constituencies and tend not to place issues related to communication at the forefront of their concerns. Perhaps this orientation results from the understandable emphasis of these groups on medical research aimed at the improved therapy, cure, and prevention of the disease in question, rather than on improving the lot of those faced with irreversible impairments resulting from its pathology.

In sum, while advocacy groups are beginning to form around the functional inability to communicate, these groups are still poorly financed and weak. It maybe that the same forces that fo-

cused public attention on orphan drugs—drugs needed by too few patients to make their development and manufacture by pharmaceutical firms sufficiently profitable—will eventually come to the rescue of orphan devices for people with ser-

ious physical limitations like those with which this case study is concerned (36). But for the time being, at least, these forces have yet to emerge or coalesce.