

Augmentative Communication News

July, 1988 Vol. 1, No. 3

For Consumers

ALS and AAC:
We Could Do Better!



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For Consumers



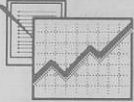
Maintaining communication
for individuals with ALS.

Clinical



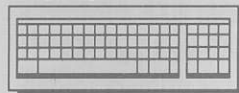
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UPFRONT

Over the past few months, I've heard from you about the May, 1988 issue. Thanks! Be sure to read Dustin's letter about light pointers. Also, see **Hints and News** on page 8.

This issue focuses on augmentative communication interventions with those who have motor neuron disease, specifically those with amyotrophic lateral sclerosis (ALS). What I initially conceived of as a single article is now squeezed into three. See the **For Consumers**, **Clinical News** and **Equipment** sections. Individuals with ALS present incredible challenges because they have critical and highly renewable augmentative management needs. Yet, when augmentative communication services are provided,

results are often profound. Intervention issues are both common to other populations and unique.

In preparing this issue, I spoke with clinicians (well known for their extensive work and research in augmentative interventions with ALS), consulted with the ALS Association, literature, manufacturers, and reflected on my clinical experiences, recalling what I've learned from individuals with ALS. Thanks to all who so willingly shared their experiences, perceptions, and great talent (see reference list).

I'm not saying that subscribers to ACN can take ALL the credit, but... on June 23, companion bills (Technology and Related Assistance for Individuals with Disabilities Act of 1988) were introduced (*cont. pg 2*)

Amyotrophic Lateral Sclerosis is a progressive disease of motor neurons in the human brain and spinal cord. Devastatingly, there is no cure or medical intervention to arrest the degeneration of motor function. Neurons that initiate and control voluntary movements slowly stop functioning producing spasticity, weakness, muscular atrophy and total paralysis. Cognitive functions are almost always preserved. The course of the disease is relentless, but it is not predictable.

The incidence of ALS is estimated at 1 to 2 per 100,000 people. At the time of death, 75 percent are experiencing severe communication impairments. Speech problems include mild to severe dysarthria (mixed flaccid-spastic type), anarthria, and laryngeal changes. Respiratory, chewing and swallowing problems are highly correlated with deteriorating speech. Upper extremity involvement results in writing problems and interferes with a range of other communication tasks, (e.g., computer access, typing, drawing, phone use).

At the present time the ALS Association estimates that 30,000 individuals in the United States have ALS, and an additional 5000 more will be diagnosed next year. If these numbers are accurate, more than 22,500 people in the U.S. alone (75% of 30,000) should be receiving help from AAC professionals. That is not happening!

Clinics that provide comprehensive management to individuals with ALS and their families are sprinkled throughout the world. Most individuals with (*cont. pg 2*)



Upfront (from page 1)

in the U.S. Senate and House of Representatives. Comments from Washington about the postcards YOU mailed to Senator Harkin were:
"the postcards couldn't have been better timed,"

"the colors (i.e., very bright blue, orange, red and yellow) decorated Senator Harkin's office and were hard to ignore."

Read more about this legislation in the **Governmental** section. Remember the Hotline number is (408) 649-3050.



ALS and AAC (cont.)

ALS and the AC professionals who serve them are not associated with a major ALS clinic or research center. Susan Carroll-Thomas reports from her recent international survey that most AAC professionals that see ALS clients treat only two a year.* This is due both to the low incidence of the disease and to the tendency of persons with ALS to seek help within their community rather than travel to specialty clinics. Unfortunately, many still do not know help with communication is available.

Professionals with expertise in AAC, who see a small number of clients each year, need to maintain contact with colleagues who have more extensive experience. This is particularly important because the literature reveals only limited information about communication management approaches. In addition, demographic information in the literature can be misleading. These data report wide ranges around the mean. They should be, but often are not, broken down by age of onset, whether or not bulbar symptoms exist, and perhaps most importantly, the type and quality of medical management individuals in the group have received. Therefore,

they tell us very little about people, communication problems, and how interventions should be planned

Repeatedly, clinicians I interviewed described individuals who did not fit the profile of the "average ALS patient."

Did you know that people get ALS in their twenties?

The literature reports the mean age of onset is 56 years (with a range 35-65). However, everyone I spoke with had clients in their 20s and 30s. AAC solutions will be different for small children and for those who wish to continue working or change careers.

*Did you know that no correlation exists between upper extremity and lower extremity involvement and speech and swallowing symptoms?****
(Note: a high correlation ($r = .80$) does exist between speech and swallowing problems).

Initial symptoms in ALS may begin with slow atrophy and weakness of the lower extremities, or upper extremities, or involvement of the bulbar muscles that control chewing, speaking, swallowing, and breathing. It is not, however, possible to predict how the disease will progress in any individual. Because selection of communication aids is dependent on information regarding mobility and hand function, these data suggest appropriate devices can not be selected long in advance of actual needs.

Did you know that many individuals with ALS survive well beyond 3-5 years of their diagnosis?

Clinical experience suggests (not surprisingly) that the younger the person and more aggressive the medical management, the longer people survive. Clinicians describe clients diagnosed 10 or more years ago. AAC management teams must plan for the future, even though it can not be predicted.

Referrals to AAC professionals presently come from a variety of

sources: the Muscular Dystrophy Association (MDA), family and friends of the client, the ALS Association and its chapters***; and far fewer from physicians and other health care professionals! In communities where AAC teams have made an effort to inform their community of available service, referrals increase; some now have difficulty handling new referrals.

Service delivery problems currently confronted

1. Limited information among professionals and the general public about augmentative communication interventions.
2. Too few professionals with AC expertise who evaluate and treat individuals with ALS.
3. Limited funding for assistive devices and clinical services.
4. Attitudes that families can (or should) solve communication problems by themselves.
5. Lack of coordinated and comprehensive services.

The ALS Association and the MDA often serve as primary resources to those with ALS. It is important for individuals and families who face motor neuron diseases to get linked up with these agencies immediately.

People affected by ALS need more attention from the AAC community. Increased public awareness of available options is occurring through media attention (e.g., newspaper articles, T.V., movies). However, if those with ALS are to sustain their right to communicate, we need professional and consumer advocates for AAC services within each community.

* Later this year watch for Susan Carroll-Thomas's International Project on Communication Aids for the Speech-Impaired (IPCAS) report on degenerative disease processes affecting communication and swallowing. I'll let you know how to order.

** Yorkston, K., Miller, R., Hillel, A. (1988) Management of Speech and Swallowing Problems in ALS. Proposal for Miniseminar at ASHA Convention: Boston.

*** ALS Association, 15300 Ventura Blvd. #315, Sherman Oaks, CA 91403. MDA, 810 7th Ave., New York, NY 10019.

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Clinical News

Management Principles and Practices

Augmentative interventions for individuals with motor neuron disease will incorporate many AAC management approaches employed with other groups. However, characteristics of the disease process and service delivery system for individuals with ALS require unique considerations. Discussed below are current practices and principles employed by clinicians (see reference list) recognized for their expertise in augmentative communication with ALS patients.

1. Team management.

Speaking and writing problems never occur in isolation. The primary management team for those with ALS should be a multidisciplinary team (e.g., neurologist, psychiatrist, nutritionist, respiratory therapist, occupational therapist, physical therapist, speech pathologist, nurse, and social worker). Currently, AAC professionals on ALS teams may play a dual role, e.g., a speech-language pathologist may be responsible for aspects of AAC and dysphagia* management. Generally, however, professionals with AC expertise only address issues related to augmentative communication and assume responsibility for the coordination of communication interventions with other aspects of care.

2. Early AC intervention.

Initial contact between individuals with ALS and AAC teams should occur prior to the onset of speaking and writing problems. Several advantages to early interventions include opportunities to:

- Get a sense for the personality of individuals while they can speak without effort.
- Establish a relationship with the person and family and observe family dynamics.
- Discuss various strategies to maintain speech and writing and provide information about augmentative options.

- Explore funding issues and options.
- Encourage the person and family members to express opinions and preferences.
- Provide clients with opportunities to control future decisions.
- Observe/evaluate language use.
- Discuss vocabulary selection.

During initial visits, most augmentative professionals generally assess communication needs and capabilities and provide education about the possible course of the disease and the range of alternatives available to maintain communication. In clinics that see patients regularly, some clinicians prefer to provide information gradually as the individual or family requests it. Yorkston, for example, finds waiting for patients to initiate topics decreases resistance to information provided. Her patients generally ask "what happens if I can't talk?" on (or about) their third visit.

Despite what clinicians prefer, most individuals referred to AC programs reportedly already need (or on the verge of needing) augmentative aids and techniques.

3. Service delivery approaches to AC interventions.

Many different service delivery approaches are employed in attempting to meet the needs of this population. Whereas, some AAC programs for individuals with ALS are well established, others are getting started. Most don't exist, yet.

In one approach the focus is on end-stages of the disease. Recommendations for equipment and strategies that will enable communication to continue in the face of severe motor impairment (e.g., use of an Etran, computer with single switch input for scanning, etc.) are made. The team generally helps procure equipment and provides initial training. Often, an attempt is made to find a professional in the community or designate a family member to monitor the program.

This approach is almost inevitable when clients live at a distance from the team or when services are not available at the same place the patient receives his/her primary medical care. In addition, families and individuals with ALS often come specifically for end-stage equipment (referred by professionals or themselves). Finally, third-party payers and clients may be unable or unwilling to pay for comprehensive management.

The problem with this approach to service delivery is that few clients maintain contact with the team or community augmentative specialist. Therefore, sufficient information, understanding, and adequate training to utilize recommended approaches is not be provided. Clinicians caution us: Don't assume no news is good news! YOU'll need to check up periodically to see how things are going.

Another service delivery approach being used is a serial intervention. Solutions to communication problems are provided as they occur. Regularly scheduled visits, an active follow up program, and the potential to employ rapid interventions are basic to this approach. During each visit, the team provides the best solution for the moment and the next augmentative technique, strategy and/or aid that will be needed (based on current observations and taking into account the effects of fatigue and weakness on performance and function). Individuals and families acquire information and make decisions more slowly. To implement this more comprehensive approach effectively, considerable resources are needed, including access to equipment. Unfortunately, such resources are rarely available.

4. Communication partners and caregivers.

Working with and recognizing the needs and realities of communication partners and caregivers is important to all augmentative interventions. However, the selection of aids and techniques for persons with ALS may depend (*cont. pg 4*)



more heavily on partners. Individuals with ALS can be quite flexible. For example, Kraat typically demonstrates an ETRAN, EYE-Link system and Scan chart to families and asks them to try each and make a selection. Many clients select two because some partners prefer eye pointing approaches; others prefer scanning. The client doesn't really care; he or she just wants to communicate!

5. Intervention Contexts.

Many agree that clinicians should intervene (at least part of the time) in contexts where individuals live or work. Those who visit homes regularly observe that recommended approaches are often not as effectively used as they might be.

6. Strategies to solve communication problems.

To maintain communicative competence, individuals gradually shift from reliance on natural speech (and typical writing tools) to more and more dependence upon technological and human assistance. Changes in speaking rate generally precede the deterioration of speech intelligibility. Be aware deterioration may be rapid. Yorkston reports the average length of time between intelligibility scores of over 85 percent to scores of less than 30 percent was only six months (N = 25).

Persons with ALS use several techniques at any given point in time as well as over time, to compensate for increasing impairments.

16 Tips to maintain and enhance speech intelligibility.**

Most individuals have never considered what is required to speak; it is something we all take for granted.

1. Explain how various muscles and organs work to produce speech.
2. Encourage people to discover strategies that work for them as well as try some listed below.
3. Use phrasing, e.g., one word per breath.
5. Use elongations, e.g., prolong vowels and concentrate on consonant production.
6. Exaggerate articulatory patterns.
7. Use positions and postures that provide the most support during long or stressful conversations.

Dustin on Light Pointers: A Letter to the Editor

"i feel very ugly when i wear head lights. this keeps me from being like a regular first grade boy. i felt like a wise boy because i took mine off...when i type i use arm supports that mr. gillford made for me. this is probably the only tool i have that is like my moms light hand on me.i do not want to need to talk through others but without patient listeners i do get labeled poor dustin. i keep just inventing more words for my friends. why look crazy when i talk?" Dustin Webb, age 7, May 30, 1988.

As his mother, Anne Webb points out: "Young children do have strong feelings about their appearance. Watching a three year old pick out shoes in a shoe store makes this point clear." Dustin is a child with spastic quadriplegia and resulting mobility and communication problems. He is a "gifted learner" and attends his neighborhood school. He's a finalist in the National Association of Young Writers 1988 competition for "Dustin's Trip to Space." Dustin, I hear you (and your mother) loud and clear. Children (and sometimes adults) may not always be asked for their perspective in therapy and evaluation environments. Even communication specialists forget to listen. Thanks for the reminder! Light pointers are an option; fortunately we have others. We applaud your right to decide. Have a stupendous summer-try that word out on your friends!

8. Be aware that exercises intended to strengthen weakening muscles may be counter-productive.
9. Fatigue is a significant factor. Something that "works" in the morning, may not later in the day.
10. If volume is reduced, consider using an amplifier (see equipment section).
11. If someone is on a respirator with fully inflated cuffs, an electrolarynx or respiratory tube that provides an alternate air source may be used.

When speech becomes unintelligible in some contexts or for some partners, the following additional strategies may help:

12. If writing is functional, always carry a paper and pen as a back up to speech.
13. Use a letter board to cue the listener, e.g., point to the first letter of words spoken.

If unable to point with fingers or a pointer, a scanning board or Etran can help.

14. Spell words out loud or on an alphabet board if they are not understood..
15. Establish the topic before speaking (either by writing or using an alphabet board or spelling out loud).
16. Use conversational repair strategies. (Note: Melanie Fried-Oken has a handout she provides to clients that lists lots of repair strategies.) You can get a copy from me. Please send a self-addressed envelope and \$1 (to cover mailing and copy costs).

Tips to facilitate writing.

Initial strategies to facilitate writing are the use of splints, keyguards, and various pointers. Some people like Crayola markers because they are easier to write with. Pens and pencils can also be made easier to grasp by encasing

them in rubber grips, etc. Portable typewriters with (or without) message storage and retrieval can be useful with keyguards and pointers, after use of paper and pencil becomes difficult.

When speech and writing are not functional, additional equipment is needed (see Equipment section).

7. Emotional and Psychological Aspects of the Disease.

During discussions (particularly early on) with individuals and families, a range of emotional reactions can be expected as existing and future losses are confronted.

Seven things you can do to make it easier are listed on the next page:

1. Acknowledge that assistance with communication may never be needed.
2. Make individuals aware that the team is available if they should have difficulty speaking or writing.
3. Reassure them something can be done.
4. Explain (and demonstrate) a range of options. Include strategies to maintain speaking and writing as well as augmentative aids and techniques.
5. Explain that individuals with acquired disorders compare augmentative communication techniques with normal communication and often judge the augmentative techniques and aids harshly. Help families develop realistic expectations, acknowledging problems with rate, etc.
6. Listen carefully to what people say, answer questions as they arise, and be honest about your perceptions (e.g., "you seem overwhelmed by all this equipment.")
7. Be careful not to overload people with information. Be sensitive to both spoken and unspoken reactions.

Susan Carroll-Thomas advises that it is normal to mourn losses, and people normally have all kinds of emotional and physical reactions to losses. "People who are grieving do not need help. What they need is normalizing." Persons with ALS hardly have time to recover from one loss before confronted by another; mourning may be continuous.

All interviewed acknowledged it can be tough to work with these individuals and their families. We grow to like and care about them. Professionals have to deal with loss also. When someone you care about dies, you must mourn. Only then, suggests Carroll-Thomas, will you be able to help other clients. It is important that professionals who work with terminally ill individuals recognize their own need for support and get it.

* Swallowing intervention is critical to successful management. Early consideration of options: posture, choking precautions, dietary adjustments, alternative methods of nutritional management, and monitoring by a physician and dietician will insure nutrition. "Living with ALS," is an informative article about options by Dr. Lance D. Meagher, an internist with ALS diagnosed 12 years ago. He continues to practice medicine despite being respirator dependent, tube fed, and anarthric. Write P.O. Box 296, Cannon Beach, OR 97110.

** Handouts of additional tips available: Delva Culp, Callier Center, 1966 Inwood, Dallas, TX 75235 and the ALS Association.



University and Research

The Morton Roberts AC Center

Queens College is located in a residential area in New York City. Within the College, the Department of Communication Arts and Sciences offers graduate level training in augmentative communication for speech-language pathologists. The primary goal of the program is to develop clinically competent professionals. Stipends are available

The Morton Roberts Augmentative Communication Center was established in 1981. It offers students "hands-on" experiences in the multidisciplinary aspects of assessing and treating children and adults in need of augmentative communication services. The Center provides services to persons with severe physical disability and those unable to communicate because of severe language disorders or mental retardation. Services include screenings, in-depth assessments, construction/acquisition of recommended aids, intensive and short-term speech and communication training for the severely impaired client, and training of local educational or habilitation teams responsible for implementing recommendations locally. The program emphasizes the need to extend training to interaction with parents and families and to deliver services outside the clinical setting, in schools, homes, and places of employment. The Center is well equipped with a comprehensive and contemporary inventory of augmentative devices, interfaces, and computer access equipment.

The AC Center is part of the Speech and Hearing Center, a brand new facility with conference and clinical areas, a student lounge, research laboratories, and testing suites. Approximately 20-25 speech-language pathology students are enrolled each September in this full-time, two year master's degree program. All students take at least a graduate level course, a prac-

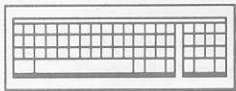
ticum, and a lab in augmentative communication. Some specialize in AC and spend more clinical practicum time at the AC Center, participate with faculty on AC research projects, attend special seminars, and take advantage of opportunities to work at the AC center during the summer. In addition, they can have special externship experiences in AC at other New York facilities. Many graduates now work in the augmentative area.

Clinical and research experiences and coursework in augmentative communication are provided by faculty on the Morton Roberts Augmentative Communication Center staff. The coordinator of the Center is Arlene Kraat, internationally known for her clinical and research contributions in AC and her commitment to graduate education. Other faculty (either on a full-time, part-time or consultative basis) at the Center are: Lucille Punzie and Marsha Siver-Kogut (speech-language pathologists), Jim Hinojosa, Karen Buckley, and Joyce Sabari (Occupational Therapists), and Ronald Arroyo (Rehabilitation Engineer). Other professionals (physical therapists, educators, vocational counselors, seating specialists and engineers) are available.

Current faculty research interests are reflected in these speech-language pathology projects:

- *Partner differences in conversing with severe nonfluent aphasics*
- *Playful teasing in the social interactions of an AC user*
- *Validity of parent reporting in AC sampling: Obligatory and optional turntaking in mother-child dyads*
- *Comparison of two rate enhancement techniques: Prediction and abbreviation expansion.*
- *Negotiation between non speakers and their partners: Establishing topic/reference.*
- *Speech synthesis applications*

For additional information contact Arlene Kraat, Queens College Speech and Hearing Center, 65-30 Kissena Blvd. Flushing, NY 11367



Equipment

Equipment needs increase as ALS progresses. Clinicians agree that nonelectronic and electronic equipment should be introduced early. When speech and writing is still possible, aids may be used infrequently; however, if available, the user can learn to operate the device before it takes on a more substantial role in meeting needs. For example, if the individual is writing and weakness is present, an alphabet board is provided for times when she (or he) is tired.

AC teams always recommend low cost solutions. In addition, more sophisticated (and expensive) high tech solutions often are recommended because they provide more independence, a range of options and new experiences. Decisions about assistive devices ultimately are made by individuals with ALS and their families. Clinical observations suggest individuals with ALS:

1. Are not inclined to select devices that require a great deal of new learning.
2. Prefer approaches that closely represent what they are already familiar with, e.g., they want to use orthographic symbols.
3. Are likely to explore available computer-based technologies if they (or someone in their family) have used a computer at home or work.
4. Are concerned about finances and may be reluctant to spend money on equipment, but many are willing to seek funding sources.
5. Need a great deal of information about what available technology can do.

Equipment to enhance communication

Note: To my knowledge, no systematic evaluations exist for devices designed to meet the communication needs of individuals with ALS. Equipment listed below was mentioned by clinicians interviewed in response to the question "What equipment do you recommend?" Please regard the information as "helpful hints from the field." See reference section for manufacturers.

1. Increasing volume of speech.

Amplifiers can increase the loudness of intelligible speech and reduce the effort needed to talk. Many recommend Radio Shack amplifiers because "they are easy to

get and low cost." The Rand Voice amplifier and Voicette Amplifier by Luminaud, Inc. are also used.

Note: Amplifiers also make unintelligible speech louder. Some patients with articulation problems think what they need is an amplifier. When the etiology of their deteriorating speech is explained, they are willing to consider more appropriate options.

2. Writing & accessing computers.

Clinicians report that portable typing aids are often favored by those who can use them. Among the direct selection typing aids recommended are: the Sharp Memowriter, Canon Communicator, QED Scribe, and Casio Personal Computers.

For the "serious writer," a desk or lap top computer with good word processing software is recommended. Computer access is a necessity for individuals who wish to pursue a range of communication options and other interests. A keyboard emulator is, of course, required. Various hardware, firmware, and software options exist. Among those mentioned:

- The Words + devices (portable and stationary), which use IBM compatible hardware (Datavue Spark, Toshiba, PC-XT hardware) and customized software options (EZ Keys/EZ Talker, WSKE, Equalizer).
- The Communi-mate with special software. Note: The ALS Association provided this information.
- Zygo's Talking Notebook and the Portable Anticipatory Communication Aid (PACA).
- The adaptive firmware card is also used when a family has, or would like to purchase an Apple Computer.

3. Conversing: nonelectronic aids.

Individuals with ALS often prefer using a pen and paper. To insure privacy, magic slates are recommended.

Alphabet boards, using direct selection by the user or scanning by the partner, are commonly introduced as speech intelligibility deteriorates. Initially the individual may point to letters. Light pointers

are occasionally used, as well (see Hints); however, fatigue and weakness in neck muscles often quickly contradict their use.

When designing an alphabet board, displays can be configured in alphabetical order, a QWERTY array, the WRITE system, or if scanning techniques are used, by frequency of occurrence. Murphy and Cook report individuals who used manual scanning boards were better users of electronic systems later on.*

Note: Wu and Voda describe an alphabet board used as a manual scanner in a hospital setting. Partners learn it in 5 minutes. It is configured in a 6 by 6 graph (36 spaces) from A to Z. All vowels are highlighted in the left column, consonants follow in order. The 10 "empty" spaces contain numbers 0 to 9. These may be used to code emergency messages. Simple and elegant!**

The ETRAN and Eye-Link approaches are often recommended because eye muscles are generally spared and normal eye contact can be preserved during conversations. Partners should be given primary consideration also when configuring the display. For example, an 8 point direct selection message board might be all that can reasonably be expected of a busy nursing staff. Close family members will use a more complex array. Have you ever seen a dyad communicate with an Etran that isn't even there (because both partners have memorized it)? As my daughter would say, "It's so BIG!"

Although the alphabet is always used, other types of displays may enhance rate. For example, pictures and codes can be used to express basic needs or recurring aspects of one's life.

4. Conversing: electronic aids.

Desirable features are:

* Multiple accessing techniques so as motor abilities change, adaptations can be made easily. Note: Scanning is considered a must, although some clinicians and clients prefer morse code because of rate advantages. However, fatigue can quickly preclude Morse Code from being a desirable accessing technique for ALS clients.

* Very good synthetic speech.

* Rate enhancement strategies (prediction, abbreviation expansion, etc.) (cont. pg 7).

* Ability to store and retrieve messages.

* Portability and ease with which individual can be set up with the device.

Among the computer-based devices recommended are the previously mentioned Words + and Zygo devices (with speech). Also, the ACS EvalPac, Prentke's Light Talker with Express software, and the Wells and Ryan's Communi-mate.

5. Telephone

Often speech output on communication devices is used with a speaker phone and an extension speaker. TTY's are occasionally used. Be sure to at least check on reduced rates from phone companies for long distance calls (because of slow rates generating messages using communication aids). Other options to consider using with the phone are modems with communication software. All types of bulletin boards and conferences are available that may be appealing. Some are free!

6. Preparing for emergencies.

Call signals are provided in most augmentative communication devices or can be made or purchased. However, the need to alert caregivers in the middle of the night can be a major cause of concern. Clinicians prefer to recommend switches that are placed on the body, e.g., a brow wrinkle switch or a pneumatic switch placed under the head activated by moderately increased effort.

Funding

Funding issues are critical to decisions about equipment. It is unacceptable for anyone, particularly people with ALS to "wait a year" to communicate while multiple appeals are made to funding agencies. Well-organized lending libraries would help to alleviate the funding problem. Some families donate equipment to lending libraries.

Note: In the U.S., proposed legislation includes a "loan program for assistive technology devices" (see Governmental section)

At present, equipment generally is purchased by individuals using personal resources (i.e., money from savings, employers, relatives). Insurance companies do cover costs in some cases, but not on the first try. Those who have funded aids for individuals with ALS are: Blue Cross, Prudential Insurance Company, Aetna Insurance Company, Equitable Life Assurance Society of the United States, and Lincoln National.

Remember, you are prescribing a communication prostheses . . . not a computer.

Other sources of funding are the Muscular Dystrophy Association, which may pay up to \$300, service clubs (Kiwanis, Rotary, Lions); and the Veterans Administration. In Ontario, Canada, government funds may soon be available for adults with degenerative conditions. How are other countries providing equipment to individuals with ALS?

The Future

A glimpse at the future reveals the expansion in microcomputer and speech technologies. We'll see smaller, more powerful aids with very good speech that are more acceptable in public. Also, incredible

amounts of available information (e.g., with CD Rom and Optical Discs) will open new opportunities and experiences for individuals with handicaps. No quantum leaps in conversational rates, however, are predicted until technology is available that "reads our thoughts."

Also in the future will be a more scientific basis for selecting devices and for moving from one approach to another. The ALS Severity Scale (see references) is a staging system designed to rate the degree of impairment of an ALS patient in the areas of speech, swallowing, lower extremity and upper extremity function. Information about the scale and data from the Neuromotor Speech and Swallowing Clinic at the University of Washington, Seattle will be presented at the 1988 ASHA Convention in Boston. You also can learn more about it at the ISAAC Conference . . . Don't forget to register!

* Murphy, J. & Cook, A. (1985). Limitations of Augmentative Communication Systems in Progressive Neurological Diseases. RESNA Proceedings 8th Conference: Memphis, TN.

** Wu, Y. & Voda, J. (1985). User Friendly Communication Board for Nonverbal, Severely Physically Disabled Individuals., *Arch Phys Med Rehabilitation*. 66



Governmental: Technology Legislation on the "Fast Track!"

According to Senator Harkin's office, the Technology-Related Assistance for Individuals with Disabilities Act of 1988 is "on the fast track." It was introduced in the Senate by Senator Harkin and in the House of Representatives by Representative Jeffords on June 23. Both Bills have many co-sponsors, representing bi-partisan support! Both have been referred back to their committees of origin for "markup," i.e., the full Committee approves it (after final changes). After "markup" the Bill is brought to the Senate/House for a vote. The target date for "getting the bill out of Senate committee" is July 13. I think it may really happen. Now it is time to contact Senators and Representatives from your State. When it passes (always be optimistic), here's what it will mean.

Title I assists States to "develop and implement consumer-responsive statewide programs of technology-related assistance for disabled individuals." States will compete for grant funds to implement a plan over 3 years: 10 states will receive monies in Year 1, 20 more in Year 2, and the rest in Year 3.

Titles 2 authorizes different government agencies to study financing of devices and services, study the feasibility of a national information and referral program, support training and public awareness grants, and fund demonstration projects for service delivery, development, and a loan program.



Hints	 News	Hints
<p>Additional information about light pointers</p> <p>Melanie Fried-Oken uses "splunking lights" (others use them to explore caves). They are low cost and quite effective for short term use as light pointers with ALS clients, she reports. Marie Capozzi-Hinchliffe says that she (and others) are trying to use a laser beam as a light pointer. Sounds interesting.</p>	<p>1. At the recent RESNA conference in Canada, the AAC special interest group was recognized for its contributions over the past year! Congratulations.</p> <p>2. Another chapter of ISAAC is being formed in the Netherlands. Thanks to H. van Balkom for that information. Work is still progressing on the U.S. chapter also.</p>	<p>1. Syndactics Bulletin: Tips for Teaching Language-Handicapped Students & Information/Edge Language and Language Disorders have combined subscriptions. It's good information for only \$17.97. P.O. Box 1004, Phoenix, AZ 85064.</p> <p>2. A nice training package (videos, book, and software) is now available. Assistive Device Center 650 Univ. Ave. #101B, Sacramento, CA 95825.</p>

Resources & References

Carroll-Thomas, Susan. The Rehabilitation Center, Ottawa, Ontario, Canada (613-737-7350).

Cohen, Carol. Adaptive Services of Enable, UCP, Syracuse, NY (315-455-7591).

Culp, Delva. Callier Center, Dallas, TX (214-783-3000).

Dublinske, Stanley. American Speech-Language-Hearing Association, Rockville, MD (301-897-5700).

Fried-Oken, Melanie. Rehabilitation Institute of Oregon, Portland, OR (503-229-7266).

Klein, Lynn. ALS Association, Sherman Oaks, CA (818-990-2151).

Kraat, Arlene. Morton Roberts Augmentative Communication Center, Flushing, NY (718-520-7358).

Murphy, Jane. Assistive Device Center, Sacramento, CA (916-924-0280).

Reardon, Geraldine. Zygo Industries, Portland, OR (503) 684-6006.

Shane, Howard. Communication Enhancement Clinic, Boston, MA (617-735-6466).

Yorkston, Kathryn. Rehabilitation Medicine, Univ. of Washington, Seattle, WA (206-543-3134).

EQUIPMENT SECTION

Adaptive Firmware Card - Switches also, Available from Don Johnston Developmental Equipment, P.O. Box 639, 1000 N. Rand Rd., Bldg 115, Wauconda, ILL 60084.

Adaptive Communication Systems, Inc. - EvalPac. Switches also. P.O. Box 12440, Pittsburgh, PA 15231.

Canon Communicator - Canon U.S.A. Inc. One Canon Plaza, Lake Success, NY 11042-9979.

Casio Personal Computer - Available at many computer stores. Can be found at discounted prices, if you look.

Etrons - ALS Association. Attention Etrons Board, 15300 Ventura Blvd., Suite 315, Sherman Oaks, CA 91403. Also Zygo.

Luminaud, Inc. - Rand Voice amplifier and Voicette Amplifier - 8688 Tyler Boulevard, Mentor, OH 44060

QWERTY array - typical typewrite keyboard

Prentke Romich Co. - Light Talker, switches, environmental controls, 1022 Heyl Road, Wooster, OH 44691

Sharp Memowriter - no longer commercially available; however, many are still around.

Wells and Ryan, Inc. - Communi-mate. 600 Pickwick Court, Mount Prospect, ILL 60056.

Words + Inc. - Laptop/Desktop computers, switches, synthesizers, special software. Distribution of products by Adaptive Communication Systems (address above.)

Zygo Industries - Etrons and mount, QED Scribe, Talking Notebook, the PACA, switches, keyboard emulators, software - P.O. Box 1008, Portland, OR 97207-1008.

Beukelman, D., Yorkston, K. & Dowden, P. (1985). Communication augmentation: A casebook of clinical management. College Hill Press: San Diego.

State-of-the-Art Management of ALS: Exploring Current Techniques, Issues, and Solutions. Proceedings from ALS Association and UCLA Extension Conference March, 1988. Long Beach, CA.

Kraat, A. Augmentative communication intervention for the adult with ALS. Mini-seminar presented at the ASHA Convention, November, 1987, New Orleans.

