Augmentative Communication News

November, 1989 Vol. 2, No.6

INSIDE THIS ISSUE . . .

For Consumers	Life after brain injury is never the same...
Clinical News	AAC's role in recovery from TBI: Issues and practices
Equipment	The role communication aids play
Governmental	Glimpse of Down Under: Part 1 New Zealand (NZ)
University and Research	The Assistive Device Center: California State University - Sacramento

UPFRONT

Since the September issue of ACN *hit the stands*, we have had some adventures! First, a trip to New Zealand and Australia where we met with colleagues and learned about AAC "*Down Under.*" You'll read more about this in the **Governmental** section, which features NZ. A pilot strike limited our ability to visit widely in Australia; however, we spent a few days in Melbourne, an active AAC haven. *More on Australia in the next issue.*

Returning to northern California, we arrived just in time to *feel the earth move under our feet*, i.e., for the Earthquake. Suffice it to say, no one here is looking forward to the Big One!

The primary focus of this issue is the role of AAC in the lives of individuals who have sustained severe brain injuries as a result of a trauma, i.e., traumatic brain injury (TBI). **In For Consumers**, characteristics of the population, and issues confronting families are discussed. The **Clinical** section highlights strategies currently used by professionals who work with this population at various stages of the recovery process. **Equipment** considers light and high tech aids and computer applications. Many thanks to the talented, committed professionals whom I interviewed *(see list of Resources)*. In the **University/Research** section, the Assistive Device Center - California State University in Sacramento is highlighted. *(continued on page 2)*

For Consumers

AAC after TBI: Silenced by the epidemic

Traumatic brain injuries (TBI) affect approximately 1 in 500 people each year. In many countries TBI is the #1 killer of persons under age 34. Nearly half of adolescents and young adults affected are involved in high-speed motor vehicle accidents. Children (and the elderly) are more likely to be injured as a result of falls (50%) or low-speed vehicular/pedestrian accidents (33%). In the U.S. alone, 70,000 to 90,000 individuals per year sustain injuries severe enough to result in permanent disability. These individuals, who may require long-term care, tend to have relatively normal life expectancies. The financial costs of TBI can range from $200,000 for acute medical care and rehabilitation to $4 million for those requiring long-term residential placements. Everyone (governments, 3rd party payers, families, professionals, communities) is concerned about the fiscal and psychological costs of TBI to individuals and society.[1,2,3,4]

Fifty percent of individuals who sustain severe TBI survive. Of these, 2-5% remain in a persistent vegetative state, 7-14% are severely disabled, 15-19% are moderately disabled, and 12-26% make a "good recovery." Seizure disorders, visual difficulties, cognitive, communicative, behavioral, and motor control problems (including speech and swallowing) are common sequelae.[5] Most individuals are nonspeaking for a transitory period after a severe TBI. To date, however, the prevalence of individuals with persistent deficits requiring augmentative communication on *(cont. pg. 2)*

Upfront (from page 1)

For those who have elected to earn ASHA CEU's, the 1989 test is included with this issue. Instructions are attached. If you have any questions, just give me a call on the HOTLINE (408) 649-3050. Return all forms to ACN, 1 Surf Way, #215, Monterey, CA 93940 <u>before</u> December 31st.

The holiday season is fast approaching. Gary Poock, your publisher, and I wish you joy, love, relaxation, and good times with your friends and family. Till 1990!

Silenced by epidemic (from pg. 1)

a permanent basis (i.e., 1, 2, 5 years post injury) is not well documented.

Recovery from severe TBI continues for years and depends on:

- **the extent and nature of brain damage;**
- **preexisting factors** (age, pre-traumatic personality, lifestyle, prior knowledge-base, educational and vocational achievement, history of drug abuse, learning problems, and ability of family to be supportive and remain involved);
- **clinical management during recovery** (i.e., knowledge and skill of professionals and quality of care received in acute care hospitals, rehabilitation facilities, community agencies, nursing homes, outpatient clinics, schools, etc.).

After discharge from an acute care hospital, individuals with TBI go to a variety of settings depending on their medical and cognitive status. Some, with mild injuries, go home. The most severely injured, including those likely to require AAC, are admitted to nursing homes, long-term care facilities, inpatient rehabilitation centers, etc. Over years, individuals may spend time in several different facilities.

<u>Cognitive recovery:</u> Almost any type of disability can (*and does*) result from a severe TBI; cognition is **always** affected. Table I summarizes two frameworks used by professionals to track cognitive recovery from TBI. The Rancho scale, developed for adults, is the most widely used (e.g., 81% of U.S. facilities). For children, a broader framework has been suggested: Early, middle, late stages. Both serve as valuable guides for intervention planning and are used by professionals to discuss individual cases, practices, and strategies.

<u>Recovery of speech</u>: A clear relationship has been shown between level of cognition and speech recovery after TBI.[9] Studies describing the course of motor speech recovery have been setting specific (i.e., hospitals, rehabilitation centers). Because different settings serve the needs of different populations, this can be confusing. <u>Research is needed to more accurately represent the course and identify variables to predict which individuals will have persistent deficits requiring long-term augmentative communication</u>. Yorkston, Honsinger, Mitsuda, & Hammen[10] investigated the prevalence of speech, swallowing, and cognitive problems in 151 patients seen across 3 medical treatment settings in the Seattle area: acute medicine, acute rehabilitation, outpatient rehabilitation. Their findings illustrate differences across treatment settings, confirming the need for caution in generalizing data.

- Acute medical setting - speech problems = 40% (25% non functional); cognitive levels = Rancho levels 1-8.
- Acute rehabilitation settings - speech problems = 65% (20% non functional); cognitive levels = Rancho levels 3 to 8 (mostly 4 and above).
- Outpatient rehabilitation program - speech problems = 20% (10% non functional); cognitive levels = Rancho levels 5 to 8 (mostly 7 & 8.)

Their data suggest 20-25% of patients in acute inpatient settings and 10% of those in their outpatient programs had nonfunctional speech secondary to motor speech problems (dysarthria).

Keenan[11] provides a glimpse of a more severely TBI group. She followed 100 patients from admission to discharge (mean = 6 months, range 2-18 months) at a facility that provides care for those who function at Rancho levels 2-5. Not surprisingly, at admission nearly all patients were nonspeakers. At discharge, half were still not speaking. One third of those who were discharged went to a rehabilitation hospital (*most were talking*); one-third were sent to nursing homes (*most were <u>not</u> talking*); and one-third left to go home or to group home (*about half were talking*).

Table 1. Cognitive Frameworks for Intervention

1. Rancho Los Amigos Levels of Cognitive Functioning[6]

<u>Level 1</u> - no response. **<u>Level 2</u>** - reacts inconsistently and nonpurposefully to stimuli. **<u>Level 3</u>** - begins to respond in a localized manner. **<u>Level 4</u>** - very confused, agitated, and quite bizarre. **<u>Level 5</u>** - not agitated, but confused and inappropriate, responds to simple commands. **<u>Level 6</u>** - depends on external structure, able to demonstrate goal-directed behavior. Appropriate, but easily confused. **<u>Level 7</u>** - appears quite normal, but judgment remains impaired, permanent deficits are becoming apparent.
<u>Level 8</u> - purposeful and appropriate, demonstrates decreased abilities relative to pre-morbid levels.

Note: Whereas some may move from level 1 to 8 in a matter of hours/days, individuals with severe TBI may remain at level 3 for long periods. Many individuals never reach level 8. Respondents to a recent survey of rehabilitation facilities report most individuals seen for AAC function between Levels 3 and 6. Only 20 percent function at levels higher levels.[7]

2. **Early, Middle, Late Stages**[8]

<u>Early</u> - minimal response unless stimulated, limited recognition and attention. **<u>Middle</u>** - confused, agitated by environment, short attention, cognitive disruptions. inconsistent **<u>Late</u>**, - residual deficits apparent, oriented, able to function independently in less structured environments and learn new information, cognitive inefficiencies.

Questions about when, how long, and what factors predict a return of speech are difficult to answer. <u>Long-term, longitudinal studies tracking individuals over time and across settings are needed</u>, particularly those defining in detail the nature of speech and communication problems. Case studies are helpful.[12, 13] For example, Light, Beesley, and Collier[14] described an individual who used various AAC techniques prior to recovering speech 3 years after the injury. Others report individuals whose speech returned up to 9 years later.

AUGMENTATIVE COMMUNICATION NEWS is an independent, non-membership publication. Copyright 1989 by Sunset Enterprises. Reproduce only with written consent.
Author, Sarah W. Blackstone, Ph.D.; Publisher, Gary K. Poock, Ph.D.
Published by Sunset Enterprises, One Surf Way, Suite #215, Monterey, CA 93940
Subscriptions: By personal check U.S.$37 (1 yr), U.S.$67 (2 yrs), U.S.$97 (3 yrs). Single issues $8.
Overseas - U.S. $47 (1 yr.), U.S. $85 (2 yrs.), or U.S. $123 (3 yrs.).
Institutions, libraries, schools, hospitals, all others: Add $20 per year. Single issues $10.
Special rates for consumers and full-time students now available.
ISSN #0897-9278 Telephone (408) 649-3050

Consumer issues:

Access to Information: Many countries (Canada, United Kingdom, Australia, Switzerland, U.S.) have head injury associations that provide broad based, consumer-oriented networks, information exchange, and advocacy.

Access to Qualified Personnel: Until a few years ago, few university training programs offered coursework in either AAC or TBI. In fact, professionals in rehabilitation centers report receiving training "on-the-job," and through self study and continuing education.[7]

Families need to seek out AAC professionals who have the experience necessary to manage the communication needs of individuals with TBI. Those who have not worked in facilities specializing in TBI rarely have the level of expertise necessary to understand the complex cognitive (and resulting behavioral) characteristics of individuals with TBI. Why?

It is the speaking TBI patient who teaches us about the cognitive and communication factors involved. If we have only seen physically handicapped, non- speaking individuals after TBI, we have not had an opportunity to observe the typical confusion, and many other problems that exist. Just because we don't observe something. . . doesn't mean it is not there.

Likewise, professionals who specialize in TBI may lack current information about augmentative communication or fail to realize the role it might play in facilitating, as well as compensating for, the recovery of speech and communication skills. Vendors and professionals with expertise in AAC need to collaborate with colleagues specializing in TBI to insure the individual's condition, cognition and recovery pattern are well understood before making recommendations for equipment. Professional collaboration also provides increased opportunities for facilitating long-term recovery.

Access to Funding: The TBI population seems to have more access to money for services than other populations (i.e, those with cerebral palsy, degenerative conditions). Caution should prevail with regard to AAC aids and services. One study in the U.S. showed that although 75% of recommended aids were funded, only 25% were bought by 3rd party payers.[9] Insurance companies (public/private) are beginning to require professionals to demonstrate functional goals and are asking for **outcome measures.** *(See ACN, Vol. 2, #3)*

Acceptance: Anticipate inconsistencies. Individuals with TBI often reject equipment. Some may be unaware of their unintelligible speech, listener reactions, or even the presence of a communication aid. Others, with more intact cognition, may reject devices finding even the most sophisticated sorely lacking when compared to "normal" communication. Some reject AAC for cosmetic reasons or because they simply are not ready to accept any option.

Families may also refuse to consider AAC aids and techniques. Learning to accept the presence of a long-term disability is part of the recovery process. Clinical psychologists or social workers familiar with TBI can help. Professionals should keep an open door and try to present options in ways that are acceptable. For example, introducing an aid as a way of helping someone participate in a program, as a typing device, or to help out in just one situation, is a start.

Follow Up: As with other populations, follow up is needed. Persons with TBI continue to change, and the process needs to be monitored by a team of specialists. Three major problems are identified

1) individuals who are not treated at all,
2) those who are fitted with an aid and not provided with necessary training.
3) those whose systems of communication are not being updated on a regular basis.

In conclusion, consumers and professionals need to work together to improve the services delivered to those individuals with TBI who have persistent expressive communication problems, particularly after they leave the rehabilitation system.

Clinical News

Goals and guidelines for using AAC

Experts caution those who work in AAC not to look at individuals who are severely speech and/or writing impaired as a result of a severe TBI as you would someone with a developmental disability, a degenerative disease, or even a stroke. Only the speaking brain injured resemble this group. Even so, no individual is like any other. In assessing, prescribing, implementing augmentative communication options, AAC professionals must either be well acquainted with the population or collaborate with professionals who are. Two areas are particularly problematic:
1) inability to predict the future and
2) complicated cognitive issues.

Because cognitive deficits underlie many of the communication, language, and behavioral problems observed in people with TBI, intervention is typically considered under the umbrella of cognitive rehabilitation, i.e., remediation of cognitive deficits (aspects of attention, perception, memory, organization, judgment, reasoning, and problem solving) interfering with functional performance. Strategies are devised to provide an individual with the structure and support, i.e., scaffolding, they require to function. This often means limiting the amount, rate, type of information individuals have to deal with so they can carry out daily activities (e.g., use a communication aid to interact).[8,15-20]

AAC techniques are being used to accomplish 3 goals:

- 1. developing a response mode to assist in understanding an individual, i.e., a **diagnostic tool**
- 2. facilitating aspects of the recovery process, i.e., **a therapy tool.**
- 3. providing a means of communication to insure participation and meet an individual's changing communication needs, i.e., a **communication prosthesis.**

On the next page , a summary of information shared by those interviewed is presented as guidelines for using various AAC techniques at each stage of recovery. *Please see list of resources.*

(cont. pg. 4)

Table II. Guidelines for Early Stages of Recovery

1. Provide stimulation to all modalities, observe motor responses.
2. Encourage social responsiveness, choice making, acceptance/rejection through eye gaze and natural gestures.
3. Reinforce any attempt to initiate.
4. Use social automatic behaviors, i.e., "hi, how are you doing today?" Look for the slightest response.
5. Develop yes/no. Try to elicit/facilitate use of a natural head nod/shake gesture and teach staff/family to recognize, elicit, and reinforce. Keep questions simple. Interview friends and family. Ask about wants/needs or individual's interests, activities, background, family.
   Note: Keenan reports a yes/no response emerging between Ranchos levels 3 and 5 (56% level 3; 20% level 4; 24% level 5). In 11% of cases, yes/no response was established one year or more after injury.
6. If necessary, teach alternate ways to signal (e.g., thumb up/down). A yes/no communication display (printed words or "smile" face) can be used if you take into account visual problems. Some suggest pairing with bright colors (e.g. yes/green; no/red). Coded yes/no responses (i.e., 1 finger= yes, 2 fingers= no) are not recommended at this stage of recovery; however, if the code is re-taught prior to each response, some can manage.
7. Once a consistent yes/no system established, introduce word or picture boards with a few symbols. There are no hard and fast rules in selecting symbols. Visual problems are very common. Use what is most familiar, recognizable and meaningful. Many adolescents and adults retain some literacy skills. So, try words. With children, simple symbols (perhaps brightly colored) are preferred over photographs, which are often confusing. Placement of symbols on the display must be done carefully taking into account visual field cuts, figure ground problems, blurred vision, double vision.
8. Use communication boards to work on cognitive processes (i.e., attention, selection, categorization) as well as prompt patients to communicate simple needs or make choices. Color coding may assist categorization.
9. For those unable to directly select items on a board, a simple listener-assisted auditory scanning technique may be used (see ACN Vol.1,#5). If possible, professionals/family can point to symbols as they speak to encourage visual scanning.
10. For those whose prognosis for motor recovery is poor, simple switches may be introduced to turn on a radio, etc. Some try dial scanners and light pointers. Realize these techniques are unfamiliar so individual can not rely on former knowledge.
11. Repeat instructions, provide cueing and frequent orientation information, and give continuous support.

Early stages (Levels 1-3)

Master clinicians are recommending we attempt to re-establish communication early. **Don't wait** for people to reach a certain level (e.g., Rancho V) or even to be "medically stable."*

Characteristics: Inconsistent performance, confusion, need for external structure, disorientation, lack of initiation and inhibition, limited comprehension (i.e., simple, context-bound), severely impaired learning, perseveration, and visual-perceptual problems.

Focus of intervention: a) monitor cognitive, communication/linguistic, motoric status, b) re-establish basic communication (i.e., basic needs and social exchanges), and c) train partners in techniques. See Table II for a list of 11 intervention guidelines in the early stages of recovery, Rancho Levels 1-3.

*Note: The Western Neuro sensory stimulation profile:[21] was developed to assist professionals to study the recovery process and evaluate treatment programs. It is sensitive to subtle changes (Levels 2-5). Very nice!

Middle stages (Levels 4-6)

Nearly 80% of individuals being seen for augmentative communication are functioning at Levels 3 through 6.[7]

Characteristics: Intermittent agitation, confusion, and inappropriate behaviors. Use of previously learned skills, e.g., spelling. Difficulty integrating new with old information. Ability to deal with increased number of symbols and accomplish more complex communication tasks. Limited (or no) awareness of communication/speech problems. Lack of initiation. Perseveration. Ability to go through steps to operate a simple device, with support.

Focus of intervention: a) provide a highly structured environment, b) control communication tasks to insure success and prevent inappropriate behavior patterns from developing, c) train partners to provide scaffolding and act as facilitators. Table III provides 16 guidelines for intervention.

Table III. Guidelines for Middle Stages of Recovery

1. **Realize communication boards provide partners with evidence the individual has something to say and is capable of interaction. This can be very important in and of itself.**
2. If an individual is agitated (level 4), there is not much you can do. Decrease input, observe purposeful movement and signs of communicative intent, e.g. rejection.
3. Continually evaluate size, type, placement, and number of symbols.
4. Involve person in process of developing boards (e.g., where should items go) to facilitate categorization, organization, attention, etc. Gradually increase vocabulary. **Note:** Decisions about vocabulary selection and expansion must take into consideration the cognitive problems of each patient. Experts in TBI feel quite strongly that an individual's ability to participate in a "vocabulary selection activity" at this stage is quite limited. . . if we use typical selection techniques (see ACN Vol. 1, #5). They require individuals to "brain storm," a difficult task for people with cognitive deficits.
5. Begin using topic specific boards as both a comprehension and expressive tool to facilitate participation in activities. Gradually increase number and complexity of boards/vocabulary.
6. Provide concrete memory strategies (e.g., written instructions).
7. Consider introducing (not buying) a simple electronic system for those who begin spelling. Select keyboard that is already familiar.
8. Simple devices with voice output may be useful in some cases. (Loop-tape recorder, IntroTalker, Parrot, MacCaw, Wolf.) However, sometimes voice output is distracting, e.g., one person began to laugh every time he heard the speech synthesizer, immediately forgetting the topic.
9. Train operational sequence. Provide visual and verbal cues (Number steps #1, **turn on switch; #2 press symbol**)..
10. Train functional use in structured settings. Keep environmental variables/tasks very simple.
11. Realize generalization is a big problem. Individuals forget: a) they have a device/aid, even when it is with them; b) sequences, i.e., how to turn it on; c) what a communication aid is for; d) preprogrammed messages.
12. Cue person to recognize communication breakdowns. Put a few repair strategies on a board or lap tray, "I need to start over." " Can you repeat that?" At this point realize individuals rely on a "trial and error" approach.
13. When person selects same topic over and over, don't remove it. Highlight or circle it, cueing them to pick something else.
14. Be sure to observe what an individual is doing across contexts, partners, and conditions.

15 Model elaborations of person's messages on their board or device.

16. In nursing facilities, expect communication aids to disappear. Be sure to make plenty of back up copies. Also, make videotapes to show staff how aid/device operates and how person uses it to communicate.

Late Stages (Levels 7-8)

Communication characteristics secondary to cognitive deficits include perseveration, lack of initiation, topic shifts, inability to repair breakdowns, lack of attention to partner cues.

Characteristics: Learning inefficiencies, persistent deficits, which are now apparent, and splinter skills.

Focus of intervention: a) learn compensatory means of functioning, b) accept disabilities, c) retrain old skills and build new ones, d) train partners to provide scaffolding and act as facilitators. Table IV has guidelines for late stages of recovery.

Table IV. Guidelines for Late Stages of Recovery

1. Be prepared for a low frustration threshold secondary to the brain injury and the individual's increasing awareness of his persistent disabilities. The slow rates of communication possible using AAC techniques is often unacceptable.
2. Negotiate. Don't make decisions for people. Be prepared for inconsistency in acceptance/rejection of aids and strategies. For example, many individuals want to spell everything out and do not want partners predicting. Many refuse to use telegraphic strategies. After negotiating a plan, write it down and make it available to partners.
3. Practice in non functional settings until person is comfortable. Don't expose individuals to real situations until they have achieved some degree of competence. Increased stress often will result in disorganized behaviors.
4. Consider using electronic aids first as a writing prosthesis, developing skills in interaction later.
5. Provide written instructions and/or self-prompting strategies.
6. Refine transmission techniques. Evaluate whether you can move from row-column to group-item scanning and from direct selection spelling to coded messages or prediction. Organize stored words/phrases in a manner logical to person (e.g., alphabetically or by category).
7. Speech appliances. Consideration of palatal lift requires referral to a cranial facial team with individuals who understand issues related to velopharyngeal intervention with TBI. Yorkston[22] reports success fitting Rancho Level 6 patients if they are changing rapidly, have adequate respiration, even those with no tongue movement.
8. Develop metacognitive strategies to enable person to deal with persistent deficits.

9 Provide opportunities to practice in real situations with support, i.e., community, classroom.

Equipment

Communication system components for the TBI

The communication systems of individuals with TBI typically have multiple components at one time (e.g., speech, gestures, communication board, electronic device), as well as multiple components over time.[11,12,13] As discussed, the type of aids recommended must take into account the individual's cognitive, physical, perceptual, emotional status and the fact that everything is likely to change. Flexibility is key. Consider also the following:

1. Those with TBI tend to use direct selection devices. Very few use scanning.
2. DeRuyter and Lafontaine[9] reported 77% of communication aids recommended for nonspeaking patients were nonelectronic, i.e., word, alphabet, and picture boards.
3. Selecting electronic devices that emphasize old, rather than new learning, is important, e.g., those with reasonably intact literacy skills want to spell using a familiar keyboard array. Many have difficulty with encoded techniques and machine prediction.
4. Cosmesis is a big factor for adolescents and adults, i.e., small, unobtrusive aids with gender-specific speech. Many reject any speech output.
5. Visual displays are a problem because of visual problems mentioned. Be careful.
6. Computers are tools that can be motivating, consistent, provide repetition, and allow a person to control the stimulus. They also have psychosocial benefits: a) partners may perceive person more favorably b) an individual's self esteem may improve, or c) a person may feel less self-conscious about re-learning how to construct a sentence, subtract, etc. Note: Don't use a computer with an individual who is agitated or currently experiencing seizure activity.
8. Clinicians did not recommend software specifically developed for those with TBI. Early on, use cause-effect programs to see if and how a patient responds to simple cause/effect programs.. Later, educational software is used to re-establish access to old knowledge. Also, programs are preferred that emulate features of communication devices or develop skills (i.e., word processing, data entry) that can be of educational or vocational value later on.

In early stages of recovery, clinicians use simple choice boards, preferably nonelectronic. During middle stages, nonelectronic communication displays (boards, Etrans, listener-assisted auditory scanning) prevail with a gradual expansion of the number of boards and vocabulary available. Symbol sets and display configurations are carefully individualized to account for visual perceptual and other problems. Topic and activity boards are widely used. Clinicians also begin introducing dedicated electronic devices. Often mentioned were the Casio, Canon, Zygo notebook.** Some are trying simple speech output devices (e.g., IntroTalker). In later stages, multiple modes are typically recommended, and multi-purpose communication devices are considered. Additional devices mentioned were: Speech Pac and Touch Talker with Express software. A warning: Just because an individual demonstrates an ability to use hand gestures, a communication book, a dedicated device and a computer in structured settings does not mean he/she can do so in real environments. Again, training is critical.

There is a concern about sophisticated electronic devices being purchased by schools, families, insurance without considering the cognitive demands. Even when devices are prescribed by those who carefully match features to a person's abilities, preliminary information suggests that only half are being used as designed, 1 to 3 years later.[23] Reasons probably reflect many variables (cognitive, psychosocial, and service delivery factors.). We must be cautious. If devices are to be implemented appropriately, we must better understand the problems currently existing.

Casio Portable pocket typewriter/computer. $179.95. Crestwood Company, 6625 N. Sidney Place, Milwaukee, WI 53209. Phone (414) 352-5678 Fax (414)352-5679

Canon Communicator M $424.95. Crestwood Company or Canon USA, Inc. One Canon Plaza, Lake Success, NY 11042, Phone (516) 488-6700.

SpeechPac. Adaptive Communication Systems, Inc., P.O. Box 122440, Pittsburgh, PA 15231.

Zygo Notebook. Zygo Industries, P.O. Box 1008, Portland, OR 97207-1008.

IntroTalker and TouchTalker Prentke Romich Co., 1022 Heyl Road, Wooster, OH 44691.

**NOTE: Many say they wish the Sharp Memowriter were still available.

Governmental

New Zealand

NZ literally sparkles with its vivid green pastures, snow topped mountains, beautiful glacial lakes with water so pure you can drink it, relaxing hot springs, an occasional charming city, and of course, its sheep. Over 3 million people and 70 million sheep live in NZ.

The North and South Islands of New Zealand are comparable in size to California or Japan. Apart from Antarctica, New Zealand is the last major land mass to be explored. The first humans to arrive (about 800 A.D.) were descendants of the Maori people and comprise approximately 10% of today's population. Although the 1600 and 1700s brought European explorers, "settlement" of NZ did not take hold until the 1800s, sparked by missionaries and the discovery of gold.

Historically, NZ has been a socially progressive country. Free, compulsory, secular public-school education was created by law in 1877. Two years later every adult male was given the right to vote. NZ women began voting before most other countries. Today NZ is a self-declared nuclear free zone and environmentally conscientious.

A socialistic society, NZ provides pensions to all citizens who are older, poor, ill, and/or are disabled in an accident. Currently however, economic problems (e.g., federal deficit spending) and demographic characteristics of the population (e.g., aging) are causing a crises in health-care, education, and other social programs.

> The impact of radical Government restructuring in the areas of education, housing and health, combined with redundancies, increasing unemployment and the extension of the user-pays philosophy" is affecting service delivery throughout NZ. (T. W. Cunniffee, 1988)

Currently, minimal government resources in NZ support research and professional training in AAC related areas or consumer access to services and equipment. To address these needs, a national coordinated policy was proposed in 1987 by the *Working Party on Assistive Communication Devices*. Although not yet implemented (i.e., funded), the proposal designated Communication Assessment Centres to provide assessment, prescription, and implementation training in the use of communication devices. To report on AAC *"Down Under"* we visited:

The Centre for the Handicapped and Technology (C.H.A.T.) at the Auckland Crippled Children Society. Staff implement an interdisciplinary, center-based service delivery model, seeing approximately 40 children and young adults each year. *Claire Oakley-Brown*, Coordinator, and *Christine Williamson*, Speech-language therapist (SLT), currently working in a nearby hospital Board facility, shared their many insights and perspectives on service delivery in NZ.

Augmentative Communication Centre at Burwood Hospital in Christchurch. *Viviane Mulgrew*, Acting Charge, SLT, *Roska Maas Griffin, SLT, and Barrie Woods*, Technical Officer (TO) described the team that conducts approximately 15 AAC and computer access evaluations per year for adults. In discussing both high and low tech solutions, they stressed the importance of providing training programs to individuals and caregivers.

The Communication Aid Assessment Centre under the Palmerston North Hospital Board's Speech Therapy Department is established at the **NZ Disabilities Resource Centre**. *Sally Winter*, Chief, SLT, *Helga Pratt*, OT; *P. Cunniffee,* Information; *Derek Smith*, Executive Officer; *Geof Isles* Deputy Director(TO), and others described their work. The NZ Disabilities Resource Centre provides client services, product development and information and focuses on seating and mobility aids. An approach to technology applications, which integrates mobility, communication, and environmental control is their goal. At present, about 100 clients a year are seen for mobility and seating aids; many also require communication equipment.

We also visited the **Waikato Hospital** in Te Awamutu. *Karen Houghton*, *Caroline Barnes*, Training officers, and *Stephen James*, Psychologist, estimated that of the approximately 300 intellectually impaired people living there, only 5 communicate well. We discussed NZ law and their *Guidelines for standards for services for people with intellectual handicaps.* They describe difficulties training staff and community personnel to implement programs. Unfortunately, the importance of communication training is not yet widely recognized as a critical component of deinstitutionalization and integration.

Our colleagues in NZ face familiar problems:

1. **Low-incidence population.** Demographic data report the rate of severe speech handicaps in NZ at 5.84 per 1000 preschoolers and 13.95 per 1000 school age children. Adult conditions range from a rate of .01 per 1000 (Motor neurone disease) to 1.28 per 1000 (intellectually handicapped.)

2. **Isolation from rest of world.** Professionals work hard to stay in touch and keep up with activities in the U.K., U.S., & Canada. They do it too!

3. **Professional education.** At the present time most AAC professionals are "self taught" or have been trained overseas. Preservice education is in a state of transition. Speech-language therapists and special educators attend Christchurch College of Education where SLT training was recently extended to a 4 year degree program. Occupational and physiotherapists attend Technical Institutes in Auckland and Dunedin, which also may change over to a 4 year degree program. Inservice training activities (e.g., conferences, workshops) for professionals and consumers are limited. The 12 Disability Resource Centres in NZ provide professionals/consumers a potentially rich source of information exchange network.

4. **Access to equipment.** Most communication aids, AAC materials, peripherals, and software must be imported causing two major problems: 1) Prohibitive costs (e.g., device + shipping + 12.5% government tax + duty= **LOTS OF MONEY.**) 2) Lack of manufacturer support. The NZ market is small. Few manufacturers have distributors that know the products well enough to provide needed support causing serious problems for NZ professionals & consumers. **Attention manufacturers:** They need your help.

5. **Funding.** Funding is available through the Department of Social Welfare and/or the Accident Compensation Corporation. However, most people with congenital, degenerative, and acquired conditions (not caused by accidents) must rely on family savings, philanthropic trusts, community organizations, cake sales, etc. A unique source for funding is NZ Lottery "Grants to disabled individuals." They purchase aids that "improve independence and quality of life."

Colleagues in NZ are working hard to serve the needs of individual clients, remove barriers, and affect public policy by increasing the knowledge and understanding of administrators, health-care professionals, educators, rehabilitation personnel, legislators, and government agencies. They are making headway. The formation of a NZ chapter of ISAAC, or perhaps an ISAAC-Australia/NZ, could be a mechanism for advocacy, information exchange, and training. Organized AAC consumers and professionals are powerful catalysts for change. Why not start off with a NZ-AU AAC conference! What do you think?

NOTE: If you have information/products to share/sell (e.g., manufacturers, publishers, organizations), please add these folks to your mailing list!

C.H.A.T., Box 6450, Auckland, NZ Phone: (09) 735-026; Fax: 649-303-2106. Attn: Claire Oakley-Brown,

Augmentative communication aid centre, Burwood Hospital, Private Bag, Christchurch, NZ Phone (03) 831-311. FAX (03) 640-476. Attn: Viviane L. Mulgrew,,

Christchurch College of Education, P.O. Box 31-065, Ilam, Christchurch, NZ Phone: (03) 482-0591 FAX (03) 484-311. Attn: Sanya Heeney,

Communication aid assessment centre and NZ Disability Resource Center, 840 Tremaine Avenue, Palmerston North, NZ Phone: (063) 62-311. FAX: 063-61950

Waikato Hospital Board, Tokanui Hospital, Private Bag, TeAwamutu, NZ FAX: (07) 871-8231. Attn: Dr. Jan Scown,

9 States receive 1989 Technology Assistance Grants

CONGRATULATIONS! Strong consumer involvement played a major role in which proposals were successful. Contact the following people and agencies to find out "how they do it."

Arkansas - Dept. of Human Services, Rehab. Sue Gaskin (501) 682-6689
Colorado - Rocky Mountain Resource & Training Institute. Donald St. Louis (303) 420-2942
Illinois - Dept. of Rehab. Services. Lawrence Rau (217) 785-7091
Kentucky - Dept. for the Blind. Charles McDowell (502) 564-4754
Maine - Dept. of Education and Cultural Services David Stockford (207) 289-5950
Maryland - Governor's Office for Handicapped Individuals. Gertrude Jeffers (301) 333-3098
Minnesota - Governor's Advisory Council on Technology for People with Disabilities. Rachel Wobschall (612)297-1554
Nebraska - Dept. of Educ. Jason Andrew (402) 471-3645
Utah - UAP at Utah State University, Development Center for Handicapped Persons. Marvin Fifield (801)750-1982.

TAKE NOTE: Deadline for 1990 funding is December 1st. Good Luck!

University & Research

Assistive Device Center
California State University - Sacramento,

The **Assistive Device Center** (ADC), located in the School of Engineering and Computer Science, has three major areas of emphasis: Education, Research and development, and Client services. This article focuses on its education and research activities. Co-directors, Drs. Colette Coleman, Professor Speech Pathology and Audiology, and Albert Cook, Professor, Biomedical Engineering, foster an interdisciplinary approach at the ADC.

Educational Programs. Five courses are offered at least once a year to students from biomedical engineering, speech pathology, special education, and psychology. *Assistive devices for the disabled; Application of assistive devices; Design of assistive devices for the disabled; Delivery of assistive devices; Applications in alternative and augmentative communications.* The Center provides students with a wide range of clinical experiences. ADC staff (biomedical engineering, occupational therapy and speech-language pathology) assess approximately 60 clients (all ages and disability types) each year for communication, computer access, job access and seating. Other educational activities include inservice workshops (e.g., *Using assistive devices to implement educational and vocational objectives*; *Using the Apple computer with severely disabled children and adults*) and a resource center, which maintains a 24 page catalog of ADC administrative reports, assessment materials, book, videotapes, and computer software. Last year, more than 300 rehabilitation counsellors were trained in the area of assistive technologies.

Research and Development Activities ADC staff have carried out several federally funded projects over the past 10 years. They recently developed six training modules (printed materials, videos, and software) for speech pathology students and professionals for the U.S. Department of Education. Development projects also include work on what is now the Zygo Notebook. Research at ADC reflects the interests and expertise of the staff, students, and other faculty at CSUS. Current projects include:

Developing interaction skills in disabled children using a robotic arm. (A. Cook). In a series of studies, researchers have developed a robotic arm and are investigating its application to problems of disabled infants and children. The goal of the project is to prevent the development of "learned helplessness." The "arm" is a computer operated anthropomorphic structure that can rotate, flex and extend at the "elbow and shoulder," flex extend, supinate and pronate at the "wrist", and open and close a two finger gripper. The arm may be programmed to perform a series of movements or accomplish tasks of interest to the infant. For example, bringing a cracker within reach, shaking a rattle, operating toys, picking up and retrieving objects. Results show children over a developmental age of 8 months associate switch activation with the arm's activity. In a study examining the quantity and quality of interactions (i.e., an event during which an individual actively controlled an object or communicated with the examiner), five subjects used a single switch to control a contingent event. The number and variety of their interactions increased. Children preferred functional activities to passively watching novel movements.

Studies of motor behavior and learning in people with cerebral palsy (A. Cook, M. LeGare, S. Hussey). A series of studies aimed at understanding and developing motor control are yielding results that show movements are quantitatively different in subjects with cerebral palsy. These data are being applied to the development of motor training paradigms. Master's theses contributing to this research include: Application of Fitts' law to arm movements in people with cerebral palsy (P. Brano); The characterization of upper limb movement in people with cerebral palsy (V. Bravo); Myoelectric control on the minimover robotic arm as a therapeutic tool for cerebral palsied children (B. Tse); Increasing object use opportunity for severely disabled young children (D. Westphall). Designing, building and testing equipment to record eye movements (J. Coltellero); Identifying critical parameters of muscle disorders and providing guidelines for retraining the muscles (K. Pitsillides.)

A digitally encoded diphonic speech synthesizer with unlimited vocabulary (C. Coleman, T. Grey). The goal of this project is to develop a speech synthesis system using concatenated diphones. Specifically, investigators are developing a software program to translate existing phoneme text-to-speech programs into ones that can output diphones. They also are exploring ways to "house" the synthesizer in a small, lightweight keyboard device. Student theses contributing to this research are: The design and evaluation of a single board computer that satisfies the fidelity, real-time speech processing, cost, size, and power requirements of a portable diphone-based speech synthesis system (M. Burk); Development of a text-to-speech algorithm which uses a diphone rule table (L. Savidge); Data compression techniques for a diphone-based speech synthesis system (S. Stephens); Development of an algorithm to concatenate diphones to improve the quality of a diphone based speech synthesis system (L. Thornton).

(continued on page 8)

Augmentative
Communication
News

(cont. from page 7)

Other research projects at ADC are:

- Analysis of various letter and word arrangements to determine the most efficient array for scanning (J. Kerfoot with Dr. Coleman)
- A training project with dysarthric speakers to determine if their speech can be made more intelligible to a computer recognition system (D. Vosseler with Dr. Coleman)
- Designing and evaluating equipment for wheelchair mobility (Dr. R. Cooper).

For additional information contact Drs. Coleman or Cook, ADC, CSUS, 6000 J Street, Sacramento, CA 95825. Phone (916) 278-6422. FAX (916) 278-5949.

References

[1] Fields, J. (1976) A study of the epidemiology of head injury in England and Wales. London: Department of Health and Social Security.

[2] Ewing-Cobbs, L., Fletcher, J., Landry, S., & Levin, H. (1985). Language disorders after pediatric head injury. In J. Darby (Ed.) Speech and langauge evaluation in neurology: Childhood disorders.

[3] Tonkovich, J. (1988). Speech and langauge disorders associated with various neuropathologies. In N. Lass, L. McReynolds, J. Northern, D. Yoder. Handbook of speech-langauge pathology and audiology. Toronto: B.C. Decker, Inc.

[4] National Head Injury Foundation Fact Sheet, 333 Turnpike Road, Southborough, MA 01772 (508) 485-9950

[5] Anderson D. & McLaurin, R (1980) Report on the national head and spinal cord injury survey conducted for NINCDS. Journal of neurosurgery, Supplement, 53,S 1-43.

[6] Hagen, C., Malkmus, D., Durman, P. (1979). Levels of cognitive functions. In Rehabilitation of head-injured adults: Comprehensive physical management. Downey, CA Professional staff association of Rancho Los Amigos Hospital.

[7] DeRuyter, F., Doyle, M. & Kennedy, M. Who is doing what for the nonspeaking traumatically brain injured (submitted for publication.)

[8] Szekeres, S., Ylvisaker, M. & Holland, A. (1985). Cognitive rehabilitation therapy: A framework for intervention. In Ylvisaker, M. (Ed): Head injury rehabilitation: children and adolescents. Pittsburgh, College Hill press.

[9] DeRuyter, F. & Lafontaine, L. (1987). The nonspeaking brain-injured: A clinical and demographic database report. AAC. 3:1, 18-25.

[10] Yorkston, L., Honsinger, M. Mitsuda, P. & Hammen, V. (Dec, 1989). The relationship between speech and swallowing disorders in head injured patients. Journal of head trauma rehabilitation.

[11] Keenan, J. (personal communication),

[12] DeRuyter, F. & Donoghue, K. (1989). Communication and traumatic brain injury: A case study. AAC. 5:1, 49-54.

[13] Carlisle, M. & Culp, D. (1988). Evolutionary stages in augmentation for brain-injured patients: Clinical framework. Presented at ISAAC Biennial Meeting, Anaheim, CA and ASHA Convention, Boston, MA.

[14] Light, J., Beesly, M., & Collier, B. (1988). Transition through multiple augmentative and alternative communication systems: A three-year case study of a head-injured adolescent. AAC. 4:1, 2-14.

[15] Hagen, C. (1981). Language disorders secondary to closed head injury: Diagnosis and treatment. Topics in language disorders, 1, 73-87.

[16] Ylvisaker, M. & Szekeres, S. (1986) Management of the patient with closed head injury. In R. Chapey (Ed.) Language intervention strategies in adult aphasia. Baltimore: Williams & Wilkins, p. 474.

[17] Beukelman, D. & Garrett, K. (1989). Acquired communication disorders. AAC. 112-113.

[18] Ylvisaker, M. (1988). Augmentative Communication. In Head injury rehabilitation: Management of communication and language deficits. Houston: HDI Publishers.

[19] DeRuyter, F. & Becker, M. (1988). Augmentative communication: Assessment, system selection, and usage. AAC. 3:2, 35-44.

[20] Keenan, J. (1989). Assessment tools for severely head-injured adults. Cognitive Rehabilitation, March/April.

[21] Ansell, B., Keenan, J. & de la Rocha, O. (1989) Western Neuro Sensory Stimulation Profile. Available $39.95, Western Neuro Care Center, 165 North Myrtle Avenue, Tustin, CA 92681.

[22] Yorkston, K. (personal communication)

[23] DeRuyter, F. (personal communication)

NEWS

Congratulations to RESNA, awarded the NIDRR contract to provide technical assistance to U.S states. The goal is to build consumer res- ponsive technology assistance mechanisms. Contact Karer Franklin, Proj. Dir. 202-857-1199.

Resources

David Beukelman, Barkley Memorial Center, University of Nebraska, 402-472-5463.

Robin Burkholz, Daniel Freeman Hospital, Inglewood, CA 213-674-7050 x3328.

Roxanne Butterfield, Don Johnston Developmental Equipment, IL 312-526-2682.

John Costello, Communication Enhancement Clinic, MA 617-735-8392.

Delva Culp, Callier Center, Dallas, TX 214-897-3000.

Frank DeRuyter, Molly Doyle, and Mary Becker Kennedy, Rancho Los Amigos Medical Center, Downey, CA 213-940-7682.

Judy Keenan, Western Neuro, Tustin, CA 714-832-1941

Nola Marriner, Children's Hospital, Seattle, WA 206-526-2104

Shirley Szekeres, Rehabilitation Institute of Pittsburgh, PA 412-521-9000.

Mark Ylvisaker, New Medico Rehabilitation & Skilled Nursing Center, Schenectady, NY 518-374-2212.

Kathryn Yorkston, Rehab. Medicine, Univ. of Washington, Seattle, WA 206-543-3134.

**Augmentative
Communication
News**

One Surf Way
Suite #215
Monterey, CA 93940

PLEASE FORWARD