

Augmentative Communication News

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UPFRONT

I just finished reading the book *Mindfulness* by Ellen Langer, Ph.D., Chair of the Social Psychology program at Harvard.¹ It's a synopsis of theory and research exploring differences between doing things "mindfully" and living "mindlessly." She writes

We know our scripts by heart. In the routine of daily life we do not notice what we are doing unless there is a problem. Locking ourselves out of a car or throwing socks in the garbage instead of the laundry basket jolts us awake. William James tells a story of starting to get ready for a dinner party, undressing, washing and then climbing into bed. Two routines that begin the same way got confused and he mindlessly followed the more familiar one. (p.43)

Langer cites multiple examples of the advantages of taking a "mindful" approach to our work, health, education, recreation and daily experi-

ence. Being "mindful" means being open to new information, aware of multiple perspectives, and able to create new categories. This issue of ACN advocates taking a "mindful" approach to the "widespread anecdotal reports of consumer dissatisfaction and the frequent abandonment of prescribed technological solutions."² **For Consumers** summarizes how assistive technology is perceived and why it is abandoned. **Clinical News** looks at collaborative approaches to equipment selection. **Equipment** considers performance evaluations of communication aids, and **Governmental** inspects the role of protecting consumers. Finally, **University/Research** highlights projects underway at the National Rehabilitation Hospital in Washington, D.C. (continued on page 2)



For Consumers Rethinking the basics

Consumer. "One who buys goods or services for personal needs only, rather than to produce other goods."³ In the area of assistive technology, the term *consumer* is replacing "client" and "patient." Why?

- Assistive technology is a rapidly expanding industry and market, particularly in areas utilizing computer technologies like AAC.
- People with disabilities are among the fastest growing market segments in the world. This is particularly true when "consumer" is defined by functional characteristics (e.g., problems with mobility, communication, etc. caused by advanced age and/or disabilities) rather than diagnostic categories (e.g., cerebral palsy, aphasia).⁴
- "Client" and "patient" connote a passive role, with professionals making most of the decisions. The term *consumer* acknowledges **upfront** that the personal needs, preferences, idiosyncracies, style, and resources of people who benefit from assistive technology (i.e., individuals with problems and their families) have a direct and unequivocal impact on whether and how devices are used. To successfully transfer technology into use, it is necessary to recognize and build on the expertise of the consumer as his/her own long-term "technologist."⁵
- *Consumers* have a right to choose. People aren't born "good consumers;" but they can learn to be . . . sometimes from their mistakes.

(continued on page 2)



(UPFRONT continued from page 1)

The "old ways" are not working. They haven't been for a long time. Taking a "mindful" approach to solving the problems causing assistive technology to be abandoned brings new information (reasons why people underutilize or abandon devices); multiple perspectives (information about what consumers and professionals really think about assistive technology services) and new ways of looking at and doing things (processes that build consumer respon-

sive systems). The biggest step forward may already have been taken . . . consumer involvement! What consumers think and what they need is inherent to the design, development, evaluation, delivery, and successful use of assistive technologies. As consumer involvement increases, abandonment of devices by persons with disabilities should decrease and the process of technology transfer should be more successful. Sometimes we may wonder if we can make a difference. We can! By being "mindful" in our work, like those interviewed, and caring, of course. Till July! Sarah W. Blackstone, Author

For Consumers (cont. from page 1)

Who is the AAC consumer?

Communication devices, other assistive technologies and the systems delivering them are meant to benefit the end users, i.e., individuals for whom they are designed. In reality, however, many AAC devices are purchased by third party payers (e.g., school districts, government agencies, medical institutions, insurance companies). As a result, payers sometimes perceive themselves as the primary consumer. Examples include:

- When an agency makes multiple purchases of the same device "so staff does not have to learn to operate several devices" or because "it's cheaper."
- When the "least expensive alternative" is purchased despite an individual's demonstrated ability to benefit from more sophisticated technology,
- When administrators tell staff not to recommend any more communication devices this year because "we have no money," ignoring individuals' needs.

Overlooking the real consumer, i.e., end user, and making decisions based on cost and convenience rather than on which devices and services meet a persons's current and future needs, does not benefit people, and increases the likelihood equipment will be abandoned.

Device abandonment

Nearly one third of all purchased assistive technology devices are

abandoned.⁶ Since many consumers of assistive technology use more than one device (8 is the average), that adds up to lots of abandoned equipment.⁷ Reasons people reportedly abandon devices include:⁸

- it did not improve independent functioning
- servicing and repair were too difficult to obtain or were expensive
- device was too difficult to use, performed unreliably or required too much assistance from another person.

Other reasons for abandonment are variables having nothing to do with technology: Changes in personal priorities regarding activities, changes in the user's functional performance, difficulty obtaining devices from suppliers, and no consideration of user's opinion in the selection process.⁹ Another factor is "timing." Researchers report abandonment of technology is more likely to occur during the first year after it is recommended.¹⁰

Outcome studies

Outcome studies provide information about the actual effects of services and equipment. DeRuyter and colleagues report outcome data on the use of AAC devices with two nonspeaking populations.²

- **Traumatic brain injuries (TBI).**¹¹ One year after delivery and training on an augmentative communication system (ACS), only 56% of 25 TBI nonspeakers were using their systems in the manner for which they were designed, 24% had totally discarded them, and 20% were only using the ACS in certain environments (e.g., out-

patient therapy). Why? Two thirds of those who had discarded their systems had recovered speech. One third had upgraded their original systems. Despite what could have appeared as a poor outcome, ACS's had served an important short-term need.

- **Cerebral vascular accidents**¹² (CVA/stroke). An independent panel judged the use of ACS with 23 nonspeaking CVA individuals. 100% of the systems recommended were judged to be appropriate at discharge and 83% were judged appropriate six months later. However, six months post discharge, only 43% of these individuals were using their systems and 39% had abandoned them.

Outcome studies lead to a more mindful approach because they provide new information and perspectives, which challenge us to rethink intervention approaches. For example, newly disabled individuals seem to need a period of time after they return home to become familiar with their changed needs and to learn the relationship between these needs and the technologies that can help. Perhaps purchases could be delayed and devices loaned and/or rented during that first year.

Consumer-based evaluation criteria

Professionals are beginning to learn how expert users of assistive technology evaluate equipment. Batavia and Hammer¹³ asked a panel of experts with mobility impairments and a panel of experts with sensory impairments to identify and prioritize general evaluation criteria for 11 different types of assistive technologies.

Note: Voice output communication devices were not included, but telecommunication and writing aids were.

A total of 17 criteria were identified. The four most highly ranked criteria for all devices were:

- **Effectiveness.** Does the device do what is claimed? Are specific needs of the consumer met and in what way? Are other needs compromised?
- **Affordability.** What is price? What are costs of maintenance and repair? Are costs within consumer's means or other financing? Are there warranties and how do they affect costs?
- **Operability.** Is it easily accessible and usable? Are visual display/auditory features acceptable? What care is involved? Is start-up time excessive?
- **Dependability.** What is prior breakdown history of the device. Where is such information obtained? Is any special environment required? What problems arise if not operated according to prescribed instructions? Does it remain dependable?

Researchers: Why not ask AAC users and family members to rank and prioritize criteria for VOCAS, for access technologies, for communication boards, etc.

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Increasing Consumer Participation

A strong movement is underway to change existing delivery systems and make them more consumer responsive, i.e., increase control and participation by consumers.¹⁵

Principles of consumerism

The Four Big Cs reflect what consumers are looking for in other markets and also are goals for AAC service delivery: **C**onvenient service, **C**hoice in selection and the ability to personalize whatever one buys, **C**ourteous and prompt delivery of goods and services; **C**ontinuity and reliability of services.¹⁶

Alternatives to the Professional Expert Model

Various methods can be used to capture the expertise of consumers in the design, development, selection, procurement, and use of technology. Focus Groups and Participatory Action Research (PAR) are two examples:

Focus Groups.¹⁷ This method was recently used to examine consumer satisfaction with assistive technology services in the United States Vocational Rehabilitation System.^{18,19} Focus groups were held with rehabilitation counselors and with consumers. A majority expressed frustration with the system and felt services available for the delivery of assistive technology needed a major overhaul. See Table I for specific recommendations.

Participatory Action Research²⁰ (PAR). This sociological methodology evolved from efforts to help organizations carry out major change processes. PAR involves the practitioner, researcher, and consumer as co-participants in identifying and solving problems. Examples in the area of assistive technology?

1. Marcia Scherer²¹ used PAR to create products to help professionals and consumers identify incentives and disincentives influencing an individual's use of devices:

- 1. MPT model (Matching Persons to Technology) (See *Clinical News*)
- 2. Three assessment tools based on the model (See *Clinical News*)

From Consumers of Assistive Technology	From Counselors
Increase client advocacy activities/appeals process Educate clients about technology Provide mechanism for "hands on" experience with devices Provide sensitivity training to counselors Hire more counselors, particularly individuals with disabilities. Hire rehabilitation engineers Train counselors about technology Institute voucher system Reduce paperwork requirements Reduce delivery time Establish equipment loan closets Solicit outside contributions for technology Solicit feedback from clients on quality of services Publicize availability of VR services in community	Provide basic technology training to all counselors Utilize technology specialist & establish mechanisms for easy/quick access to specialists Improve communication with technology prescribers such as physicians Actively involve the client in technology decisions Provide pre-purchase equipment trials for clients Eliminate vendor contract systems Increase amount of funds available for purchases Remove dollar caps on specific classes of high-tech devices Hire benefits specialists to coordinate funding Streamline device approval/procurement process Restrict bids to local or regional vendors Evaluate bids on quality as well as price

● 3. **Living in the State of Stuck.** Scherer's book about 10 assistive technology users over a 5 year period. Available from Brookline Books, Inc. P.O. Box 1046, Cambridge, MA 02238 (617) 868-0360

2. Consumers, practitioners, researchers, manufacturers, their representatives and government officials recently used PAR to ask and answer six questions during a Consensus Validation Conference on Augmentative and Alternative Communication Intervention in Washington, D.C. from March 23-26.²²

- 1. What is augmentative and alternative communication (AAC)? Who can benefit?
- 2. What are the nature and scope of AAC interventions? The essential components?
- 3. What relationships should exist among consumers, "family," service providers, community, manufacturers, researchers, and funding sources to achieve effective outcomes?
- 4. What are the effective consumer and societal outcomes and benefits that can be expected from AAC intervention?
- 5. What is the relationship of AAC to expressive and receptive communication processes?
- 6. What are the research and educational issues that need to be addressed?

According to William Graves, Director, National Institute on Disability and Rehabilitation Research:

"Research efforts are shifting away from the old model of the researcher in control of research design and formulation of research questions. . . We are moving toward Participatory Action Research . . . Because of consumer involvement, we have asked and answered more relevant questions about AAC intervention and we will disseminate more relevant and acceptable intervention strategies for managing problems."²³

Being an Informed Consumer

Technology users and their families need to educate themselves about devices and services and develop coping strategies to achieve the most benefit from assistive technology and the service delivery system. Unfortunately consumers and their families are often unprepared for these challenges and may not know what resources, services or funding are available.²⁴ The best way to become an informed consumer of communication devices is to collaborate with knowledgeable professionals and ask lots of good questions. Table II. *Questions to Ask Manufacturers and their Representatives*, is a start!

How long have you been in business?	Has this device been tested? How?
How many of these have you sold?	Has this device been approved? By whom?
Can I speak with someone who is using this product?	How much does the device cost? What are the "hidden costs" (e.g., maintenance)?
Where is the closest service center?	How often are these returned for repair?
Will a loaner be provided if the device needs to be repaired?	Is there a warranty that comes with the device? What are the details of it? Does it include parts and labor?
Is any training provided with the device? Is there a charge for training?	Can I rent one? Will I benefit from improvements you make in the future? How?



Clinical News

The Selection Process: Ideas and strategies

Okay. **OKAY!** Yes! There are problems . . . If you don't think so, just read the comments below!

- **PERSON:** pertinent features of the individual's personality and temperament.
- **TECHNOLOGY:** salient characteristics of the equipment.

Along a continuum from optimal use to abandonment, a person may be an optimal user of the technology itself, but a reluctant user of the technology in some milieus. Or, a

professionals/educators consider all relevant influences: decide on appropriate training strategies in certain situations; provide funding rationale for device and training; and demonstrate improvement in functioning over time.

Available from Scherer Associates 486 Lake Road, Webster, NY 14580. (716) 475-6438.

TABLE III. What's Being Said about Assistive Technology Delivery Systems. . .Ouch!

<p>* Traditionally medical and education systems tend to encourage selection based on what professionals believe is correct and the consumer/family is expected to agree²⁵</p> <p>* The present dissemination of rehabilitation technology is limited in part by poor communication channels and uneven evaluations dominated by anecdotal self-assessment by device developers.²⁶</p> <p>* While rehab engineering settings are very responsive to the physical needs of individuals with disabilities, there is frequently less attention given to the psychological and social aspects of assistive device use.¹⁰</p>	<p>* Assistive technology seems to lend itself to making decisions about equipment based on what we know how to use, or what is our particular favorite, rather than considering the person's needs or interests and then matching all the options for these needs into a series of choices for the consumer to make.²⁵</p> <p>* Decisions about devices are often based on a clinician's past experience with previous patients and products or the contents of a sales pitch or sales literature.²⁷</p> <p>* Great concern/activity is generated about selecting and purchasing devices. Often, less effort goes in to the training required to use them.²³</p>	<p>* In the rehabilitation technology field at the present time, there does not exist a recognized, comprehensive, or even minimally adequate system for implementation and follow-up of technological devices once they are built and delivered to disabled users. It is assumed that 'no news is good news', but that <u>can</u> also mean the device is 'sitting in the closet.'²⁷</p> <p>* Successful linking of consumers with appropriate technology does not end with selection and purchase of a device. Ongoing training and support in the use, maintenance, repair, and replacement of devices is essential for effective daily use of technology.²⁴</p>
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Selection is not simply about "equipment." It is a process that entails adapting a device to a person's abilities and temperament and adapting the person to the realities and situations of device use.¹⁰ AAC consumers and clinicians are faced with a fast growing and changing market, and many do not have the resources available to determine which device(s) will work. A recent emphasis on family-centered programs and consumer-responsive systems is changing the role of assistive technology teams.¹⁴ No longer are professionals just "evaluators" and "prescribers" of equipment. They are collaborators, helping to guide the consumer in a decision-making process. To approach the selection process with a collaborative mindset, consider trying the following tools:

1. Matching Persons with Technologies (MPT): A Collaborative Model. The MPT Model was developed by Marcia Scherer²¹ to assist consumers, families, and professionals in making informed technology decisions. Table IV illustrates components of the MPT model. Note that 3 major factors influence the use of technology.

- **MILIEU:** characteristics of the environment and psychosocial setting in which the device is used.

user who has more than one device, may be an optimal user of one device, but avoid using a second device at the same point in time.

Scherer and her colleagues have developed 3 clinical/research instruments based on the MPT.

- Technology Overload Assessment (TOA)
- Assistive Technology Device Predisposition Assessment (ATDPA)
- Educational Technology Predisposition Assessment (ETDPA)

Each has a consumer and a professional version and can be used to: identify whether people are likely to use technology; help consumers/

TABLE IV. Factors Influencing Consumer Use of Assistive Technology (MPT)²¹

		Milieu	Person	Technology
U S E	Optimal			
	Partial/ Reluctant			
N O N U S E	Avoidance			
	Abandonment			

2. Interest-based planning. This method uses principled negotiation to promote choice and avoid or resolve conflict during collaborative, decision-making processes, such as selection of assistive technology. Underlying principles are to:

- 1. Separate the people from the problem and deal with each.
- 2. Focus on interests rather than positions. List problems and talk about interests, not solutions (e.g., mobility, rather than a specific wheelchair)
- 3. Brainstorm multiple options. Make no judgements until all are discussed.
- 4. Insist on objective criteria. Narrow down options that best meet criteria.

Grady, Kovach, Lange, and Shannon²⁵ point out that having information is key to consumer participation in any decision-making process and suggest the following guidelines:

- 1. Give information about all devices the family is interested in: mobility, computers, communication, environmental controls, adapted toys, etc.
- 2. Provide information on resources and help formulate consideration of other factors, e.g., training options, vendors, funding sources, books, publications.
- 3. Present information in multiple forms: hands-on; demonstrations; loans/trial use; training; pictures; written (binders with product brochures, handouts,

lists); computer printouts. Let consumers take home written information and pictures of devices.

- 4. Organize information in logical ways, building a foundation of general knowledge from which to understand individual devices, as illustrated in Figure 1.
- 5. Present a separate "pyramid of information" on each device so consumers can understand the relationships between various devices and learn how devices can be used together.

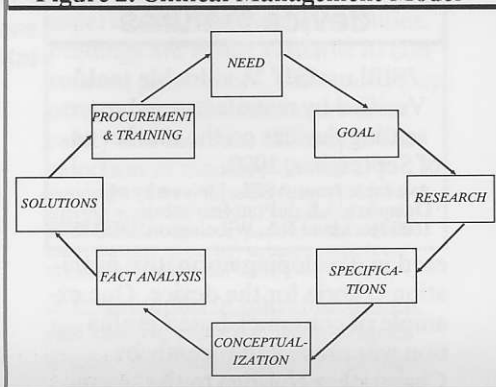
Figure 1. Information Pyramid²⁵

Provide General Technical Information "This is a computer"
Categorize Technical Information "This is an alternative keyboard"
Label Assistive Technology Device "This is the Unicorn Keyboard"
Explain how device is used "This is designed for larger movements"
Describe Applications "You can operate an educational program with this overlay"
Explore specific user applications "You can use this device for..."

3. Clinical Management Model: Importance of specifications

Figure 2. illustrates a process, adapted from an engineering Design Process Model, which I have found useful in selecting equipment.²⁸ Let's use a simple analogy . . . Shopping. Suppose you are going to a party and "need" a new shirt. Your goal is to get just the right shirt over the next weekend. How do you proceed? You certainly do not go to every store in town, trying on every shirt. No

Figure 2. Clinical Management Model²⁸



need! You've already done lots of research, i.e., you know your size, favorite color and style, stores in your area, stores in your price range, places you'll be likely to wear the shirt, weather conditions in your region, and so on. The fact is (whether you know it in a "mindful" way), you have a long list of specifications in your head before you leave home and try on a single shirt! In fact, you have prioritized your specifications (e.g., *it must go with your favorite pair of shorts and be short sleeved. You'd prefer cotton, but. . . no ironing!*).

Based on your specifications, you begin shopping. In the store, you look around and conceptualize. Which shirts best fit your specification list. Here's where you can use a good salesperson (expert!) You select a few shirts to try on. You look in the mirror, take note of how it fits and basically analyze the facts. This shirt does/does not look terrific!

Finally, you decide on one. That is your solution. You take it to the clerk and procure (buy) it. Later on, after meeting a friend for a cup of coffee, you return home and get ready for the party. Your friend loved the shirt! The party was fun and the shirt was fine, it met your need. . . except when you washed it, it shrank . . . back to the drawing board.

The decision-making process for assistive technology is similar. In my experience, a critical step that is often omitted by teams is actually listing specifications, and taking the time to conceptualize before proceeding to the next step of trying (or buying) a device. Specifications begin with the word "must." Table V gives a short example: ↗

TABLE V. Sample Specifications

- * Must be acceptable to individual and family
- * Must provide an efficient way to engage in conversational exchanges
- * Must allow him to create, store and retrieve messages, produce written work and access computers
- * Must permit him to access keyboard using index finger on left hand
- * Must allow for elbow to be supported and movement excursion of 5 inches
- * Must be elevated 2 inches 2 inches on his tray and mounted at approximately a 30 degree angle
- * Must permit use of a single switch/joy stick for leisure activities & computer assisted instruction
- * Must cost less than
- * Must have symbol configuration that permits easy access to frequently used phrases
- * Training must be available to learn mechanics of operation
- * Training in class and community must be available for at least one year.



Equipment Product Evaluations

Developments in computer technology have brought an explosion of assistive technology products and made it increasingly difficult to choose from among the many devices available. Independent product evaluations/comparisons can provide valuable information to clinicians, consumers, manufacturers, their representatives, and third party payors. Published product evaluations and comparisons exist for many types of assistive technology. One impressive example is the European Report on Wheelchairs Testing, a testing report of 11 wheelchairs tested in Europe in 1990-92. (Available from Technical

Aids Information and Evaluation Centre, Via Capecelatro 66, 20118 Milano, Italy). However, similar information is not yet available for augmentative communication devices.

Evaluating available products and/or comparing the performance of similar products is tricky. While a wheelchair does what it does, communication is a complicated process. By definition, then, assistive technologies involved in enhancing communication options are often complex and their effectiveness often depends on variables having little to do with equipment. Nevertheless, those interviewed suggest basic principles apply in the evaluation of all assistive devices. For example, both engineering and clinical analyses are needed. Engineering considerations include safety issues and determining



whether the device does what it says it does or if available, meets an established standard for the device category. Clinical considerations take into account ease of use, experience with the device, how it is used, who uses it, published reports and interviews with users.

Developing procedures to use in product evaluation requires several steps and input from multiple groups (clinical specialists, engineers, manufacturers, consumers). Even during the evaluation process, methods, procedures and documentation undergo constant review by experienced engineers, clinicians, manufacturers, and consumers. Ideally, results are disseminated to consumers, manufacturers, clinicians, and 3rd party payors. It's a dynamic process.

An important component of the evaluation process is consumer-based evaluations. While evaluation of technology by the user remains unexplored in a systematic manner which would be comparable across centers to allow for data review and action, the consumer must be the ultimate evaluator of whether a device is/isn't satisfactory. Consumers who have used devices for an extended period are in the best position to offer factors to be consid-

Comparison of AAC device features

"Still useful." "A valuable tool."
Verified by manufacturers' representing devices on the market as of September, 1990.

Available from ASEL, University of Delaware/A.I. duPont Institute, 1600 Rockland Rd., Wilmington, DE 19899

ered in developing normative evaluation criteria for the device. One example of consumer-based evaluation was presented recently by Christopher Nobriga to the Northeast Communication Enhancement Group. He compared two programs *Handikey* and *Scanning WSKE* giving "positive and negative thoughts" and delineating "problems." Through interpreters Dick Lytton and Lisa Irwin Miller, Chris indicated the need for sharing information about products.

(Note: if you want a copy of his speech, send him a self-addressed, stamped envelope).

Formal performance evaluations of AAC devices are being done. Both Sweden and England require devices to be tested before they can be funded by government programs. In Ontario, Canada, the Ministry of Health requires that AAC devices be evaluated prior to allowing them to be placed in the

loan program or purchased for individual users (see Governmental). The Assistive Device Center in Pennsylvania collects data about performance, maintenance, and use of equipment. For example, Coleen Haney reports data about breakdowns and repairs and student use of devices suggests AAC devices require very few repairs and in general, good support from manufacturers. Now and then, they find a "lemon," a device that keeps breaking down. Of the 1000 devices purchased, 822 are currently in the field with students. They also have 2000 pieces of equipment for short term loan. Unfortunately (for the rest of us), both the Ontario and Pennsylvania group are unable to share information in any formal (or informal) way because of legal issues.

Equipment evaluations need to be rigorous, as objective as possible, and carried out by experts who use a well-established protocol that is adhered to. It is only a matter of time. The performance of AAC devices and a critical comparison among those that purport to do similar things, will eventually be available to consumers, practitioners, the manufacturers, and third-party payers.



Governmental Decreasing the likelihood devices and people are abandoned

Professionals, governments, organizations, and agencies are recognizing the need to provide consumers of AAC technologies some protection with regard both to equipment and services. Few examples exist throughout the world where specific clinics/centers are authorized to deliver AAC services and prescribe or loan equipment. Bristow recently addressed a concern about the lack of standards in AAC in her testimony at the Consensus Validation Conference (*Augmentative and Alternative Communication: Are we a recognized field?*)

In Ontario, Canada, the Ministry of Health provides augmentative communication equipment and services to children and young adults through an assistive device program. Over the years, they have developed several processes to insure services and equipment are provided in a timely, efficacious manner. They have a network of recognized centers with staff with expertise from multi-

ple disciplines that conduct evaluations, recommend equipment, and provide training in the community. Recently, a pilot project was established to enable individuals to "borrow" equipment. The project is called the Centralized Equipment Pool Project (CEPP), directed by Nora Rothschild and administered through the Hugh MacMillan Rehabilitation Centre Augmentative Communication Service. Goals are to:

- improve access and support to clinicians' efficacious use of high technology equipment
- improve communication among clinicians, clinics, manufacturers, vendors, and the Assistive Devices Program
- provide timely repairs to devices owned and operated by CEPP
- improve clinical applications and provide short term loans
- improve the mechanism for delivering devices to authorized clinics
- promote expansion and growth of the present system.

Processes in place include assessment, training and equipment evaluations. Efforts are underway to make AAC equipment evaluations and outcome measures more objective (e.g., counting amount of time a device is being used each hour).



University & Research

The REquest REC & more
National Rehabilitation Hospital

Located in Washington, D.C. the Rehabilitation Engineering/Assistive Technology Program benefits from the expertise of strong clinical departments at the National Rehabilitation Hospital (NRH) and ready access to national and international forums. Major projects underway involving assistive technology are described below:

REquest REC: The Evaluation of Assistive Technology

Jan Galvin, Director

The REquest Rehabilitation Engineering Center (REC) on the Evaluation of Assistive Technology is funded by the National Institute on Disability and Rehabilitation Research (NIDRR). Although evaluation of augmentative communication and access technologies is not a current focus of the Center, it is likely to become one in the future:

1. National Survey on the Abandonment of Technology. Betsy Phillips, Manager.

Project goals are to identify variables associated with the abandonment of technology, assess their relative importance and recommend clinical procedures that may enhance acceptance of devices. Results of a survey of 175 individuals with disabilities (note: some are communication aid users) revealed four major causes of abandonment:

- inadequate product performance,
- changes in the user's functional performance.
- no consideration of user's opinion in the selection process;
- difficulty obtaining devices from suppliers.

Researchers found *devices often are abandoned in the first year*. A longitudinal pilot-study of 24 patients is investigating this further.

2. Evaluations and comparative studies of assistive technology products. Kitch Barnicle, Manager.

This project conducts objective performance and clinical evaluations on specific assistive devices. Devices are tested for safety and against their own published specifications

and if available, against national and international standards. They are also evaluated by clinicians and experienced users with disabilities. Findings are made available to consumers, prescribers, third-party payors, and manufacturers to ensure safety and increase efficacy in the selection of assistive devices.

Among those evaluated to date: adapted driving controls; manual wheelchairs; patient transfer devices; patient lifts; wheelchair battery capacity; urinary catheters, scooters, ventilators, bath/toilet aids.

3. Ergonomics of universal design.

Jan Galvin, Director. This project encourages manufacturers of mass-marketed products to take a more universal approach to product design so consumers with functional limitations (i.e., those with disabilities and aging persons) can use commercially available technology.

Note: REquest staff also are advising the Consumers Union (publishers of Consumer Report) on evaluation considerations relevant to aging and disabled persons.

4. Technical Assistance. Jan Galvin, Director.

Developers and manufacturers on a national and international basis can request technical assistance, including:

- 1. Ongoing consultation service to teach developers to test and evaluate products.
- 2. A sourcebook "Product Testing and Evaluation: A Guide for Manufacturers of Assistive Technology Devices."
- 3. Demonstration and critique of products by REquest staff and consultants at the NRH Technology Demonstration Center.
- 4. Information about domestic/foreign standards development and evaluation efforts, and activities of various regulatory agencies.

5. Training and Dissemination.

Betsy Phillips, Manager. This project provides an interface among research and training projects and designated audiences.

Consumer Satisfaction with Assistive Technology Services.

Betsy Phillips, Project Director

Funded by the Rehabilitation Services Administration, this three-year project investigates consumer satisfaction with assistive technology services. A series of focus groups with rehabilitation counselors and with consumers recently revealed major problems in the Rehabilitation delivery system. Counselors and consumers agreed: counselors often lack training in assistive technology and don't know how to access existing resources and have caseloads so large they preclude

them from spending necessary time on individual cases. A plethora of bureaucratic inefficiency was described that block timely consumer access to services and equipment. A future series of pilot training sessions for consumers and providers is planned to empower persons with disabilities and facilitate better provider-client partnerships.

Composite Model for Worksite Evaluating and Accommodation.

Don Ross, Project Director.

Funded by the Social Security Administration, this 2-year research and training project aims to:

- a) increase the number of severely disabled individuals returning to work and being retained in competitive positions,
- b) increase employer satisfaction, and
- c) decrease the amount of time many persons with disabilities are on the rolls of Social Security.

Staff have developed problem-solving approaches, a curricula and materials enabling others to implement a team approach.

Hospital/Health Care Access

Jane Bennett/Bill Peterson: Coordinators;
Jan Galvin/Don Ross: Co-Principal Investigators

Funded by the U.S. Dept. of Justice, this project is designed to facilitate voluntary compliance as mandated in Americans with Disabilities Act (ADA). Goals are to enhance awareness of the application of ADA to health care facilities and increase access to a variety of settings delivering health care by:

- providing technical assistance on physical, communication, programmatic and attitudinal barrier removal,
- developing information brochures and conducting seminars, and
- generating a checklist specific to hospital and health care facilities re: accessibility and a patient/visitor survey to obtain feedback from patients and visitors.

National Materials Development on Employment Provisions

Don Ross/Jan Galvin

Collaborating with Cornell University School of Industrial and Labor Relations, project staff are developing coursework and training materials to assist employers seeking to comply with the Americans With Disabilities Act of 1990.

For more information about any of these projects, contact project staff at the Rehabilitation Engineering/Assistive Technology Program National Rehabilitation Hospital, 102 Irving Street, NW, Washington, DC 20010. Phone (202) 877-1932 FAX (202) 723-0628 TDD (202) 726-3596.

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YOUR RESOURCES

(Thanks for sharing information! SB)
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