ABSTRACT
        This feature issue of a newsletter on community
integration of individuals with developmental disabilities considers
the role of assistive technologies. It describes efforts to utilize
consumer direction, public policy, creativity, energy, and
professional know-how in the pursuit of technology-based
opportunities to enhance community inclusion, social and economic
contribution, and self-determination. Feature articles include:
"Assistive Technology: Building a National Commitment to Liberation"
(Bob Williams); "Access to Assistive Technology: A Public Policy
Status Report" (Michael W. Morris and Christopher Button);
"Facilitating Access: The Tech Act Amendments" (Tom Harkin); "TECH
TOTS Libraries: Family-Run Technology Lending Programs" (Kathleen
Gradel and Caroline McMeekin); "Great Beginnings: Assistive
Technology for North Carolina's Infants, Toddlers, and Families"
(Lawrence H. Trachtman and Patsy L. Pierce); "Special Education and
Assistive Technology: Systems Change Missouri Style" (Diane Golden);
"Bringing Assistive Technology to Transition-Age Youth in Rural
Minnesota" (J. Martin Carlson and Lisa Vervena); "Creating New
Possibilities: Courage Center's Vocational Services Computer Program"
(Jennifer Mundl); "AgrAbility: Cultivating Independence through Rural
Partnerships" (Randall L. Rutta); "Recreation: Turning Dreams into
Reality in Utah" (Marilyn Hammond); "Assistive Technology and the
Move to Community Living" (Laurel S. Mendelson); and "Aging and
Assistive Technology: Improving Services to Older Adults" (Jane Gay
and Joseph P. Lane). A list of seven assistive technology
organizations and nine print resources is provided. (JDD)

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Jay Metcalf is one of the thousands of Americans with developmental disabilities whose contribution to the workplace and the community is enhanced by use of assistive technologies. See story on page 15.

Assistive Technology: Building a National Commitment to Liberation

by Bob Williams, Commissioner, Administration on Developmental Disabilities

I use a communication device that is aptly called a "Liberator." However, it was not until I gave the keynote address at the national People First conference in Nashville in 1991 that I realized how truly liberating such assistive technology can be – not just for individuals with disabilities, but in a political sense, for our nation as a whole. At that conference I had a roomful of 900 people all chanting in unison with me and my device: WE HAVE POWER! WE HAVE POWER IN OUR HEARTS! WE HAVE POWER IN OUR VOICES! It was only then that I came to really understand the deep transformational properties of this thing we call *assistive technology!*

It was in Nashville a year later, ironically following an assistive technology systems change conference, that I learned an equally critical, yet bittersweet lesson about assistive technology – its potential and its dreams deferred. I met a woman, a contemporary of mine named Kathy, who has cerebral palsy and who at the time was living in an institution. As soon as I met her, Kathy pointed to the symbols for, "I want to go," on her communication board. Not wanting to jump to conclusions, we asked staff what she meant by this, and they replied that Kathy wanted

From the Editors

Human beings are tool makers and users. Every day with hardly a thought we use both simple and extremely sophisticated tools to travel from place to place, communicate with others, and manipulate objects in our environment.

Assistive technology is just a subset of the tools used by human beings, providing assistance in ways and places that are needed by relatively few people with significant impairments in "normal" physical, sensory and/or cognitive abilities. Because relatively few people need specific applications of assistive technology (i.e., the market is small), these applications are not easily found in the typical marketplaces (e.g., department or hardware stores, car dealerships). Often, they are unique or must be adapted for a single individual.

The limited market and the associated costs of unique applications present substantial challenges to the fullest use of technology to assist persons with developmental disabilities to participate in and contribute to their communities. But, these challenges are being met with equally substantial commitments. This issue of *IMPACT* describes just a few of the efforts to utilize consumer direction, public policy, creativity, energy, and professional know-how in the pursuit of opportunities for community inclusion, social and economic contribution, and self-determination of people who have developmental disabilities.

CONTENTS

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Access to Assistive Technology: A Public Policy Status Report

by Michael W. Morris and Christopher Button

For children and adults with disabilities, the current opportunities offered by technology innovation are a celebration of independence and access – access to jobs, to transportation, and to community. It is a celebration about unlocking power – the power of communication, of attending one's own neighborhood school, of having a home, of performing a job, and of actively enjoying the full benefits of citizenship. The reauthorization of the Technology-Related Assistance for Individuals With Disabilities Act (the "Tech Act") in March of 1994 reaffirmed that "for some individuals with disabilities. assistive technology is a necessity that enables them to engage in or perform many tasks... to have greater control over their own lives: participate in and contribute more fully to activities in their home, school, and work environments, and in their communities; interact to a greater extent with nondisabled individuals and otherwise benefit from opportunities that are taken for granted by individuals who do not have disabilities" (P.L. 103-218, Section 3). Thus, assistive technology affords opportunity for participation and acceptance in the American dream.

Changes have been fast coming. Since 1986, there have been over 25 significant outcomes resulting from targeted advocacy efforts to establish, clarify, and enhance public policy mandates for access to assistive technology (see timeline at right). The list is dynamic, changing as new public policy initiatives emerge and as advocates work to further clarify and integrate the right to technology-related assistance in many different laws and regulations affecting programs and services for persons with disabilities.

In spite of these legal mandates and policy directives, and in spite of federal and state efforts at implementation. there remains a major gap between policy and practice. In the 1993 Study on Assistive Technology by the National Council on Disability, several over-reaching issues were identified. All decisions about access to assistive technology for a child or adult with a disability involve more than funding. Although ultimately all decisions are about resource allocation, there is an interdependence between user and provider information awareness, the capacity of the service delivery system to respond in a timely way to individual needs, and access to appropriate assistive technology. It is clear that awareness, understanding, and access to

> Since 1986, there have been over 25 significant outcomes resulting from... advocacy efforts to establish, clarify, and enhance public policy mandates for access to assistive technology.

assistive technology are still too often a result of where you live, your economic class, and your racial heritage. It is also clear that federal mandates providing possible access to assistive technology for individuals with disabilities are not self-enforcing. There is a paucity of expertise from state to state among advocates, attorneys, persons with disabilities, family members and providers who can effectively weave their way through the complex web of federal rules regarding eligibility and technology funding. Presently, there is no nat..nal database or legislative mandate that calls for the routine collection of data regarding the use and source of financing for assistive technology devices and services for individuals with disabilities at a local, state or national level. Without such data, it is impossible to compare and contrast state levels of efforts and report on funding patterns and trends. Anecdotal information has documented significant differences for individuals and families with assistive technology access resulting from varied state interpretations of federal mandates within special education, vocational rehabilitation, and Medicaid laws and regulations.

Despite this current status report there is a reason for optimism in the future. The reauthorized Tech Act offers Americans with disabilities the promise of effective advocacy and systems change. A new set of priority activity mandates should focus implementation activities in every state on eliminating funding barriers, enhancing consumer responsiveness of service delivery systems, and producing more consistent decision-making at local, state and national levels that supports the right to assistive technology access across environments. A new level of activism that focuses on outcomes and results for people with disabilities and is funded by Tech Act systems change activities could finally deliver nationwide the promise of an affordable and accessible seamless system of technology related assistance.

Finally, the new mandated subcontracts with the state protection and advocacy agencies could dramatically increase the level and scope of individual client representation on assistive technology issues. The result could be more consistent interpretation and enforcement of federal mandates for assistive technology access that level the playing field and foster equal opportunity in the classroom, workplace, and community for Americans with disabilities.

Public Policy Developments Contributing to Assistive Technology Access for Persons with Disabilities (1986-1994)

• 1986

Action: Amendments to Rehabilitation Act. Added definition, expanded program requirements. *Contribution*: Clarified and expanded program benefit of major public program

Action: Section 508, Rehabilitation Act Amendments. New guidelines for federal procurement of computers. *Contribution*: Changed procurement practices, impacted manufacturer expectations of accessible design standards at lower cost

Action: Early Intervention. Created new entitlement, expanded program benefits. *Contribution*: Established new major public program

Action: Social Security Amendments. *Contribution*: Permitted tax sheltering of income to purchase technology

Action: Temporary Child Care for Children with Disabilities and Crisis Nurseries Act. *Contribution*: Provided grants to states for respite, emergency or planned supports for families with disabilities including assistance in accessing assistive technology resources

• 1987

Action: Amendments to Developmental Disabilities Act. Expanded program requirements. *Contribution*: New priority within existing public program

Action: Older Americans Act Amendments. Created new provision of assistive technology within existing program; defined assistive technology. *Contribution*: Expanded program benefit

• 1988

Action: Medi-aid Amendments. Clarified funding options and mandates. *Contribution*: Clarified and expanded existing program benefit

Action: Tech Act. Created statewide systems of technology assistance. *Contribution*: Created new funding, new public program

Action: Telecommunications Devices for Deaf Act. *Contribution*: Established new telecommunications law with access requirement within federal agencies

• 1990

Action: Americans with Disabilities Act. Employment, transportation, public accommodations, telecommunications. *Contribution*: New access requirements of private sector, access technology by expanding concept of civil rights

Action: ADA Tax Credit for Small Businesses. *Contribution*: Created tax incentives to expand access to assistive technology

Action: Decoder Circuitry Act. Design standard for televisions. *Contribution*: Required new manufacturer standard for access

Action: Policy Letter Special Education. *Contribution*: Clarified rights under existing major public program

Action: Policy Memo Rehabilitation. *Contribution*: Clarified rights under existing major public program

Action: Amendments to IDEA adding definitions of assistive technology devices and services. *Contribution*: Clarified rights under existing major public program

Action: Amendments to Vocational Education Act. Created integrated quality and equity requirements. *Contribution*: States must provide special population students (including students with disabilities) with equal access to vocational programs and provide assistive technology

• 1991

Action: Amendment to Part H of IDEA adding definitions of assistive technology services and devices. *Contribution*: Clarified rights under existing public program

Action: Policy Letter Special Education. *Contribution*: Clarified right to take technology home from school

• 1992

Action: Rehabilitation Act Amendments of 1992. *Contribution*: Expanded use of rehabilitation technology; widened scope of services and allowed choice of provider, including those for assistive technology

• 1993

Action: National and Community Service Trust Act of 1993. *Contribution*: Included a set-aside of from $5-8 million to make necessary accommodations including assistive technology

Action: New rules for Part 1308 of the Head Start Act for children with disabilities. *Contribution*: Ensured coordination of assistive technology provisions in children's IFSPs are carried over into IEPs

• 1994

Action: National Information Infrastructure Advisory Council formed by U.S. Secretary of Commerce. Includes national disability advocate. *Contribution*: Industrial leaders must review legislative and regulatory reforms impacting the electronic communications industry including disability access provisions

Action: Reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act. *Contribution*: Included set-aside and focus on assistive technology advocacy

Action: Human Services Reauthorization Act of 1994. *Contribution*: Ensured expansion of access to assistive technology through coordination of Head Start services with activities for children with disabilities

Action: School-to-Work Opportunities Act. Established national network of transition systems from school-to-work. *Contribution*: Aid to states to establish state and local partnerships between school and the workplace; presumes systems of support for students with disabilities, such as assistive technology

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Facilitating Access: The Tech Act Amendments

by Senator Tom Harkin

On March 9, 1994, President Clinton signed into law the Technology-Related Assistance for Individuals with Disabilities Act Amendments ("Tech Act Amendments"), reauthorizing for five years a federal competitive grant program designed to facilitate access to assistive technology for individuals with disabilities and their families. The original law, passed by Congress in 1988 with strong bipartisan support, authorized a competitive grant program that would enable states to designate lead agencies to coordinate activities designed to facilitate access to, and provision of assistive technology devices and services for individuals with disabilities. As the chief Senate sponsor of the Tech Act Amendments and of the original 1988 law, I am pleased to have this opportunity to explain some of the major changes that were enacted with the reauthorization.

> The new law repeats the finding first enunciated in the Americans with Disabilities Act of 1990 that disability is a natural part of the human experience and in no way diminishes the right of individuals to...enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.

Because of the Tech Act, persons with disabilities and their service providers, advocates, and family members have the opportunity and the challenge to work with local assistive technology projects to ensure that people with disabilities, including developmental disabilities, have access to appropriate assistive technology devices and services to maximize their functional potential. An *assistive technology device* is defined in the law to be "any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." The law defines *assistive technology service* to be "any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device", including such things as evaluation, fitting, training, and technical assistance.

The new law repeats the finding first enunciated in the Americans with Disabilities Act of 1990 that disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently, enjoy self-determination, make choices, pursue meaningful careers, and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society. The law recognizes the importance of access to assistive technology devices and services for some individuals with disabilities to be able to achieve the objectives of independence, empowerment, and inclusion that are at the core of our national disability policy.

The Senate Subcommittee on Disability Policy, on which I served as chair, held a hearing in June of last year to consider the reauthorization of the Tech Act. Witnesses at the hearing testified about the importance of assistive technology and the need for a continuation of the efforts to effect systems change in the manner in which individuals with disabilities access assistive technology. John Gannon, Acting Chair of the National Council on Disability, testified about the Council's Study on the Financing of Assistive Technology Devices and Services for Individuals with Disabilities, which found that assistive technology devices and services can play a major role in increasing independence and empowering individuals with disabilities in a cost-effective manner. In particular, the study found that, with appropriate access to assistive technology:

- Almost 75 percent of children were able to remain in a regular classroom, and 45 percent were able to reduce school-related services.

- Sixty-two percent of working-age persons were able to reduce dependency on family members, and 58 percent were able to reduce dependence on paid assistance.

- Eighty percent of older persons were able to reduce their dependence on others and half were able to avoid entering a nursing home.

- Ninety-two percent of employed persons reported that assistive technology helped them to work faster or better, 83 percent indicated that they earned more money, and 67 percent reported that assistive technology has helped them to obtain employment in the first place.

With the aid of an augmentative communication device, Rachel Esparza from Mendota Heights, Minnesota, testified about the importance of assistive technology in her life. In addition to the augmentative communication device, she talked about the computer with a special keyboard that she uses at school; the computer at home that she uses for homework and to ··v with friends; the special switches that turn on lights and t, help her cook with her mother; and the lift-equipped van that her family uses to take her to T-ball or swimming and horseback riding lessons.

The witnesses at the hearing and others with whom we were in contact as we considered the reauthorization emphasized some recurring themes, including the need for greater focus on systems change and advocacy activities, support for individual advocacy, consumer involvement, accountability, technical assistance, and a national classification system for assistive technology devices and services. The new law includes provisions that address each of these priorities. Below are some of the specific changes included in the new law.

- Under Title I, each state is eligible to compete for one three-year development grant, one two-year extension grant ("first extension grant"), and one five-year extension grant ("second extension grant"). During its maximum period of 10 years of federal funding, each state is expected to enable the program to continue on a permanent basis when federal funding is terminated.

- States receiving Title I grants to develop and implement a consumer responsive comprehensive program of technology-related assistance will be expected to perform six specified priority systems change and advocacy activities, unless they show that they are making significant progress in these areas and that other activities would be more likely to accomplish the purposes of the Act. The Act sets forth a range of permitted activities in addition to the priority activities, but does not mandate that states do any specific activities with their funds. This is to allow for state flexibility.

- Protection and advocacy services shall be provided by each state, and the protection and advocacy entity is required to coordinate activities with the technology program activities in the state.

- The minimum amount that a state, or the Secretary of Education on behalf of a state, must spend on protection and advocacy services shall be determined by the Secretary of Education, based on the size of the state's Title I grant, the needs of individuals with disabilities within the state, the population of the state, and the geographic size of the state.

- The bill includes an explicit process for a state to follow if it becomes subject to a corrective action plan, which would occur if the state does not make significant progress in developing a consumer responsive comprehensive statewide program of technology-related assistance. The process involves the development of a plan, the appointment of a monitoring panel to ensure that the plan is followed, and a recommendation from the monitoring panel to the Secretary of Education regarding whether the state lead agency should be redesignated. The governor retains the responsibility for making any such redesignation, if the secretary concurs with the recommendation of the monitoring panel.

- The protection and advocacy service provider in each state also is subject to redesignation if significant progress is not made in providing such services to individuals with disabilities in the state.

- The Secretary of Education will provide information and technical assistance to participating states, as well as to individuals with disabilities directly. This provision requires the Secretary to meet the information and technical assistance needs not just of their state grantees, but also of individuals with disabilities within the states.

- Fifty million dollars is authorized to carry out Title I in fiscal year 1994, and such sums as are necessary thereafter through fiscal year 1998.

- Under Title II the Secretary of Education is required to develop a national classification system for assistive technology devices and services that will be used to determine whether devices are eligible for tax deductions or credits, and for other purposes.

- Title II projects include grants for training, technology transfer, recycling demonstration projects, business opportunities for individuals with disabilities, and developing projects of universal design.

- Ten million dollars is authorized to carry out Title II in fiscal year 1994, and such sums as are necessary thereafter through fiscal year 1998.

- Under Title III of the Tech Act the Secretary of Education is also directed to award one-time matching grants of not more than $500,000 to states for the purpose of establishing alternative financing mechanisms through which consumers can obtain funds to purchase assistive technology devices and services.

- Eight million dollars is authorized to carry out Title III in fiscal year 1994, with provisions that such sums as necessary will be authorized thereafter through fiscal year 1998.

Over the years I have had the opportunity to witness the remarkable contributions that assistive technology can make in the lives of persons with disabilities. The Tech Act is an attempt by Congress to provide access to important technology to ever greater numbers of persons who may benefit. But ultimately making technology work as well as possible for people with developmental disabilities depends on our sharing ideas about ways to improve uses of new and existing technologies and challenging service delivery systems (including Tech Act projects) to improve access to assistive technology for all persons with disabilities.

Senator Tom Harkin is Democratic Senator from Iowa. As former chair of the Senate Subcommittee on Disability Policy he was instrumental in the drafting and passage of landmark legislation for persons with disabilities, including the Americans with Disabilities Act and Tech Act Amendments.

Editor's note: The authorization of funds does not necessarily correspond to actual appropriation of funds.

TECH TOTS Libraries:
Family-Run Technology Lending Programs

by Kathleen Gradel and Caroline McMeekin

Imagine watching youngsters playing with each other, with their sisters and brothers, and with their moms and dads. Imagine that many of the children have significant disabilities: some cannot talk, others cannot walk, crawl, sit up, or roll over. Many cannot play with typical toys that children without disabilities can easily use. Does it seem like a heart-rending picture? Well, it isn't in the *real* lives of many children and families across the country because what you also see is what these kids *can* do. For example:

- One toddler you'd see can't crawl, walk or even play well with "baby" toys...but when a big red plastic switch, in the shape of a circle, is connected to a battery-operated bumper car, she can make it stop, go, and bump into another car that her little sister is playing with beside her.

- Another youngster you could get to know is a three-year-old who crawls to get around in his house. His friends in the neighborhood know that he is out to play when they see him driving a red 4x4 jeep out front on the sidewalk. He makes the jeep go by pressing a switch that is mounted on the steering wheel, since his feet aren't strong enough to push on the "accelerator" pedal.

- And then there is a little boy who "sings" the verses of familiar children's songs by touching a TouchWindow screen attached to the computer; when he touches a picture, the computer "sings" one of the verses to his mom for him.

Through use of the technology that is now available, these children are equal play and learning partners with their friends, siblings, and in their families.

All of these children have moms and dads who are members of TECH TOTS Libraries across the country. TECH TOTS is a creation of United Cerebral Palsy Associations, Inc. (UCPA) that has made it possible for UCPA affiliates, along with collaborators in local communities, to establish libraries of adapted toys, switches, computers, and other resources. TECH TOTS Libraries are set up to get technology off of shelves, outside of schools, and into homes and the lives of families.

What Are TECH TOTS Libraries?

A TECH TOTS Library is a parent-run library for families who want to borrow equipment for their infants, toddlers, and preschoolers who have disabilities. The toys, computers, switches, and other materials are for children's

and families' use at home. The library is staffed by moms and dads who use technology with their own sons and daughters; key family staff are paid, while others serve as volunteers. Each library has its own inventory of fun, exciting, and useful equipment and resources, including: adaptive switches; adapted toys to use with switches; toys that have large knobs or other modifications to make them easy to use; fun toys for anyone to play with that are commercially available and that have not been adapted; computers; special equipment to make computers easier to use; computer software; books and other resources; slides, videotapes, and audiotapes; and equipment that will help children participate in home activities. Trained Parent Coordinators in each TECH TOTS Library help other families and their children choose equipment, learn to use equipment that they have not tried before, try-out equipment that they are thinking about buying, and trouble-shoot when they have problems with equipment.

How are TECH TOTS Libraries like and unlike other lending programs nationally? Like other lending programs run by local groups, some public libraries, and affiliates of national non-profit organizations, TECH TOTS Libraries:

- Work like a real library, lending equipment rather than just books.

- Give families a chance to try out equipment that may have been used at school or in early intervention programs with their children...but now moms and dads get to see first-hand what their kids can do, empowering them to be well-informed advocates for their sons and daughters.

- Sponsor and run special training events for families, including one-to-one hands-on training, toy adaptation workshops, and more.

- May charge a small membership fee or give families opportunities to give service to the library in exchange for memberships.

Distinct from other programs nationally, TECH TOTS Libraries additionally:

- Are run by moms and dads - not the traditional staff person - who have children with disabilities, and who have used technology with their own youngsters.

- Give primary emphasis to families of children ages five and younger who have disabilities.

- Lend the full range of technology equipment, including

7

(and especially) computers, along with software that meets the age, preference, and ability characteristics of both kids and families.

* Do not require families to meet typical eligibility criteria, including income minimums or maximums, attending a prerequisite number of hours of training or being evaluated for specific technology use.

What is the History of TECH TOTS?

The TECH TOTS network began as an idea conceptualized by Michael Morris and Kathleen Gradel, staff of United Cerebral Palsy Associations, Inc., a non-profit organization comprised of 155 local affiliates. The basic concept was to get technology into the hands of families by building on what the UCPAs already knew worked, namely family-to-family contacts, networking, and support.

Working hand-in-hand with one of its local affiliates, in 1990 UCPA approached the Ronald McDonald Children's Charities Foundation for a startup grant. That first grant helped to extend the inventories and capacities of seven TECH TOTS Libraries, while covering the costs associated with training two Parent Coordinators for each of the libraries and hourly wages for part-time employment of these individuals to run each library. In addition, the award financed the development of a core training curriculum and a project logo, the production of a videotape, and the printing of a project brochure.

Following that startup, in 1993 UCPA requested and received funding from the Mitsubishi Electric America Foundation (MEAF) to extend the TECH TOTS network and concept. A one-year grant allowed UCPA to add five new affiliates to the TECH TOTS roster—all technology equipment lending programs that were already in existence, but sites that needed training, technical support, and opportunities to network with other lending programs. At the same time, the grant facilitated the project's accomplishing some critical development work, including refining its training approach used to initiate new library sites and developing a marketing package to assist others in replicating the TECH TOTS concept. Although not directly funded by the grant, UCPA was able to secure funds to ensure that each site had a Macintosh LC computer added to its inventory.

Following this first-year grant, MEAF took a step that set a precedent with its funding, and awarded UCPA an extension grant. This second-cycle award, like the original McDonald's grant, has seeded core equipment dollars to six new startup Libraries. This award has also begun to pilot, with MEAF and several of its local companies, the strategy of leveraging funds and resources from local MEAF companies, through matching grants and other collaborative activities, facilitated by MEAF. Central to this extension grant is the goal, in progress, of fostering mentoring relationships between existing TECH TOTS sites and new adopters.

Being piloted in the new grant are telecommunications-based networking strategies, including (a) using electronic mail to foster mutual support and information exchange; (b) the use of online real-time meetings to make centralized technical assistance cost- and time-effective; and (c) cumulative electronic "newsletters," composed and sent online and added to by participants nationwide. The project's new electronic focus for information exchange is a natural step from the centralized teleconferencing used at its inception, paired with long-distance technical assistance via phone by which sites have traditionally accessed technical assistance.

What Are the Challenges?

Both nationally and at the local level, TECH TOTS has faced multiple challenges to its identity, growth, and maintenance, including:

* Continuing to secure both national and local funding to aid the network and individual libraries in expansion efforts.

* Growing slowly while attempting to retain the local integrity of each library to meet local needs, funding options, etc., AND at a pace that facilitates the training and technical assistance available through UCPA.

* Working in partnership with vendors and developers nationally to aid in economical ways to help libraries grow, showcase new and utilitarian equipment to families, and enhance development of their ultimate project.

* Finding the time needed for sites to keep in touch, learn from one another, and foster across-library relationships.

* Building and maintaining collaborative relationships with local groups and organizations that have common interests.

* "Keeping up with the Joneses" in terms of new and evolving technology.

What is Available to Other Organizations?

At present, TECH TOTS is a network made up of UCPA affiliates. The project has, however, developed materials and services that may be of use to others interested in the TECH TOTS concept. The following assistance and information are available from UCPA: several core materials comprising the project's marketing package; access, through UCPA's America Online Forum, to UCPA and its affiliates operating TECH TOT Libraries; and opportunities to attend trainings or secure technical assistance on a fee-for-service basis.

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Great Beginnings: Assistive Technology for North Carolina's Infants, Toddlers, and Families

by Lawrence H. Trachtman and Patsy L. Pierce

A new era of services for young children with disabilities and their families was ushered in with the passage of Part H of the Individuals with Disabilities Education Act (IDEA). Through this legislation, children from birth through age two are now eligible for a variety of early intervention services. The provision of assistive technology devices and services is included among the components of early intervention currently required by law. According to the U.S. Department of Education's Secretary, "... the purpose of assistive technology is to meet the unique developmental needs of the child, as determined on an individualized basis through the Individualized Family Services Plan (IFSP) development process." This process involves team decision-making strongly influenced by family needs and concerns.

Assistive technology can help infants, toddlers and their families in three very important ways. First, many devices such as computers and augmentative communication systems can help children learn and develop social, communication and cognitive skills. Second, assistive technology can let very young children explore and control their environments to develop self-assurance and become independent in their abilities. Third, daily living aids can enable children and families to more easily carry out routines such as bathing and feeding, thus making these activities more enjoyable for everyone involved.

Assistive technology services are required and necessary, but funding for equipment, services and training often requires creativity and optimal collaboration among agencies working with young children and their families. North Carolina has an extensive history of serving this population and is a national leader in its response to meeting the intent of IDEA's Part H. Since 1993, almost $2.5 million in federal and state funds have been used to develop North Carolina's capacity to provide assistive technology devices and services to infants and toddlers with, or at risk for, disabilities and their families. The North Carolina Department of Human Resources, Division of Mental Health/Developmental Disabilities/Substance Abuse Services, and the North Carolina Department of Environment, Health and Natural Resources, Division of Maternal and Child Health, have initiated a statewide service delivery and equipment purchase/loan system. With the support of other public and private agencies, North Carolina is developing the type of coordinated and comprehensive system of assistive technology services that is mandated by current legislation.

North Carolina's system of assistive technology services for infants and toddlers includes these key components:

- Comprehensive, multidisciplinary assessment for assistive technology provided through a statewide network of Developmental Evaluation Centers (DECs) and other evaluation resources.

- Funds to purchase equipment for families who do not have other resources available.

- Seven regional Assistive Technology Resource Centers that loan equipment to families and local service providers and provide technical assistance, training and community outreach.

- Statewide and local education opportunities for families and professionals on assistive technology topics.

- Innovation grants to support new training and service delivery models.

Recognizing the need for communication and coordination among the agencies and programs involved in this statewide initiative, a technical assistance contract was awarded to the North Carolina Assistive Technology Project (NCATP) during the initial two years of the system's development. NCATP worked primarily with the Division of Maternal and Child Health and the seven resource centers as they began to develop and implement their programs and services. Technical assistance activities have included conducting monthly teleconference calls among the funding agencies and resource center staff, developing public awareness materials, producing an equipment resource directory, coordinating publication of three information manuals (*Parent Guide to Computers and Software for the Young Child, Assistive Technology and Play for Infants and Toddlers,* and *Introduction to Positioning and Mobility for Infants and Toddlers*), conducting workshops, and evaluating systems progress and ongoing needs. This technical assistance has been extremely effective in building a strong foundation for a permanent system to benefit young children and families.

Innovation grants have been used to develop and implement a statewide computer database and electronic bulletin board system that links the seven resource centers with other local and state agencies. Additional educational materials (e.g., the training curriculum *Baby Power: A Guide for Using Assistive Technology with Infants and Toddlers*) along with equipment loan programs have also been funded through the grants. One of the most original projects loans toys to families statewide via pre-paid U.P.S. shipping.

North Carolina's system for assistive technology services to infants, toddlers and their families is beginning its third year. Continuation funding is primarily provided by the state, thus expanding the rich array of early intervention services available in North Carolina. A state level assistive technology coordinator has been hired to work closely with the Developmental Evaluation Centers, regional resource centers, and other supporting programs. This position will be important in fostering the type of collaboration needed to continue the system's development. In addition, the sponsoring agencies are emphasizing increased local needs assessments and program collaboration to improve service delivery. Teamwork among everyone working with infants and toddlers will be essential to meet the assistive technology needs of all children ages birth to three in North Carolina.

Lawrence H. Trachtman is Assistant Director of the Assistive Technology Project, Division of Vocational Rehabilitation Services, Raleigh; and Patsy L. Pierce is the Infant/Toddler Assistive Technology Program Consultant with the Division of MH/DD/SAS, Raleigh. FFI about resources developed by the NCATP contact Larry Trachtman at (919) 850-2787; FFI on other Infant and Toddler Assistive Technology Initiatives contact Patsy Pierce at (919) 733-3654.

Gillette Children's Hospital Mobile Outreach Program

Over 70 times a year, a large white cargo van with bright red letters across the side pulls into Minnesota and western Wisconsin communities and workers unload thousands of pounds of cargo ranging from high-tech computers to low-tech hammers. The red letters read, *Gillette Children's Hospital, Assistive Technology Mobile Outreach, St. Paul, Minnesota.*

The mobile outreach program began in 1985 as an adaptive equipment repair service for families and patients who had difficulty traveling to St. Paul for service at Gillette Children's Hospital. The hospital specializes in children and adolescents with chronic disabilities, including cerebral palsy, spina bifida, juvenile arthritis, brain injuries, epilepsy, and complex orthopaedic problems, as well as children who are ventilator-dependent. Today, the outreach program provides more than repairs. Highly skilled seating specialists, rehabilitation engineers, and orthotists render high-tech services, such as evaluations and consultations for communication systems and computers, environmental controls, and power mobility devices.

Besides the high-tech gear, the mobile clinic is equipped with lower tech but essential tools to repair, modify, and create special devices on the spot. A full-scale shop can be set up to meet the needs of the individuals for special technological accommodations. Families benefit by no longer having to travel to St. Paul for services. And for families of children with disabilities, traveling even a few hours can present hardships.

The outreach program – the largest of its kind in the country – offers three types of clinics. The first, the Assistive Technology Clinics, evaluate children who need assistive technology devices such as walking aids, powered wheelchairs, daily living aids, recreational equipment, and communication and educational aids. Among the specific tasks of its staff are to: (a) evaluate and assess a child's ability to use assistive technology equipment; (b) fit, fabricate or modify assistive technology equipment; (c) demonstrate and allow young people to experiment with equipment such as communication aids or computers; and (d) train children, families, caregivers, teachers, or others in how to repair or operate equipment.

The Computer/Communication Clinics provide information, demonstration, and training for communication aids. They allow children to experiment with augmentative communication aids, computer access equipment aids, recreational equipment, and daily living aids.

The third clinic evaluates the special needs of patients who use orthoses (braces), prostheses (artificial limbs), and special seating. The mobile lab is able to modify upper and lower limb orthoses, spinal orthoses, prostheses, seating systems, wheelchair adaptations, protective headgear, and recreational equipment.

One advantage of the mobile clinics is that the van carries a variety of devices that individuals can test on site. This proved helpful on one recent trip during which staff held an inservice on augmentative communication equipment at an occupational development center. Following the inservice, a speech pathologist approached the team indicating that she had been unsuccessful in finding a particular device to help a young person. Fortunately, three different communication devices were on board and were made available to them to test. Within a few days, the young person and speech pathologist had determined the appropriate piece of equipment, without leaving their hometown.

The goal of the mobile outreach program is to improve the lives of persons with disabilities by offering a service that is comprehensive, cost-effective, and convenient. For over 350 people every year, Gillette's Outreach Program is making that goal a reality.

Contributed by Dave Wilkie, Manager of Assistive Technology at the Gillette Technology Center, New Brighton, MN. FFI contact the Gillette Technology Center at (800) 933-9439 / (612) 636-9443.

Special Education and Assistive Technology: Systems Change Missouri Style

by Diane Golden

The Individuals with Disabilities Education Act (IDEA) provides guarantees and assurances of access to assistive technology for students in schools. However, translating and applying federal requirements at state and local levels can prove to be an ongoing challenge.

With the passage and subsequent reauthorization of the Technology Related Assistance for Individuals with Disabilities Act ("Tech Act"), each state has a Tech Act funded project whose mission includes supporting the implementation of these requirements at state and local levels. Such activities fall under the general descriptor of *systems change*,

> If an agency is not providing assistive technology, it is not because it does not want to, but rather it is because of policy ambiguity, lack of resources or some other reason.

which means getting systems such as education to undertake new initiatives to increase the level of compliance with requirements and/or to eliminate practices or policies that actually hinder compliance with requirements. States may also have additional requirements that exceed those at a federal level which are included in the pool of basic rights to assistive technology for students served by the educational system. The requirements of the Individuals with Disabilities Education Act (IDEA) and other pieces of legislation have focused attention on the rights of students to assistive technology and have created an environment ripe for systems change. The challenge for Tech Act projects is to capitalize on the opportunity.

Missouri's Approach

Missouri's approach to systems change for access to assistive technology in the educational setting is based on the assumption that the state level educational agency and local educational agencies want to provide assistive technology to students. If an agency is not providing assistive technology, it is not because it does not want to, but rather it is because of policy ambiguity, lack of resources or some other reason. Holding to this approach allows for a non-adversarial initial working relationship and establishes a trust that is helpful in accomplishing systems change.

Missouri's model of systems change includes two interrelated functions: policy development and policy implementation. All states develop, review, and revise their policies regarding IDEA mandates and the operation of programs under their jurisdiction. The state educational agency (SEA) is responsible for developing policies that govern the programs provided by local educational agencies (LEA's). These policies may be initiated by the SEA with no external influence or they may be developed in response to a court decision, a series of situations with individual students that creates a policy need, or other external influence. Thus one prong of systems change is the development of good assistive technology policies at a state level.

The other equally important prong is policy implementation or vigilance. No matter how good the assistive technology policies may be, they are simply words on paper if not implemented appropriately. Training is needed to assure full understanding of policies by those expected to be implementors. Training and supports are also needed for individuals at a local level to become proficient advocates for appropriate policy implementation. Policy vigilance is a never-ending requirement to assure true access to assistive technology as intended by good policies.

Policy Development

Missouri has had relatively good success in the development of supportive assistive technology policies at a state level. New Missouri policies include a clear mandate to provide assistive technology without cost to the family as needed for an appropriate education. On a more detailed level, the new state policies also provide direction for addressing assistive technology in the Individual Education Plan (IEP) document. The IEP must specify the type of assistive technology to be provided, the amount of time the assistive technology is to be utilized, the expected date of delivery or access to the assistive technology, and the anticipated duration of the assistive technology use. These added specifics will hopefully help assure that decisions regarding delivery of assistive technology are made during the IEP meeting rather than left to later discussions and negotiations. In addition, because such decisions will be documented in the IEP, individual advocacy issues will be clarified.

To assist schools to understand the policies and complicated issues involved in the delivery of assistive technology to students, the Missouri SEA has developed a policy manual that is currently being printed. The manual will be provided to all school districts as support from the SEA.

Missouri's progress in policy development is directly related to the leadership and open communication philosophy of the SEA. In addition, it is helpful to remember that state agencies may be more likely to refine existing policy rather than develop something perceived as new policy. Most if not all states will have an existing "right-to-education" policy and policies regarding the content requirements of an IEP. Thus adding assistive technology references to clarify these or other existing policies may be an easier "sell" than other approaches.

Policy Implementation

Missouri has had some notable accomplishments in the implementation of assistive technology policies, but acknowledges there is much work left to be done. Again, the

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After 20 years of special education case law decisions, there are more fuzzy, unresolved questions than ever and assistive technology questions are adding to the pool of already complex issues.

SEA is assisting in policy implementation not only by producing the policy manual, but also by including references to assistive technology in the monitoring standards used for periodic on-site review of LEA's. While the references could be more specific, the inclusion of assistive technology in the monitoring process of the enforcement agency for IDEA means that policy implementation is not just "complaint-driven." When the enforcement of policies is achieved only through case-by-case individual advocacy, the degree of implementation varies dramatically from school to school. The SEA has the ability through its monitoring procedures to accomplish broad based policy implementation that would take much longer if left only to individual advocacy efforts.

This is not to minimize the impact of policy implementation on an individual case basis. Obviously, for the student involved the impact is great and it may be generalized to other students in the district who are in a similar situation. Neighboring schools in Missouri also communicate fairly regularly with each other (the education grapevine) and an individual case decision is likely to have some impact in surrounding area schools.

Probably most critical to impact for policy implementation at an individual level is the adequacy of the network of individuals and organizations who support advocacy. Can individuals get advocacy support when it is needed? Is the advocacy support of good quality? Is the network of individuals and organizations cohesive so that the full continuum of self-advocacy to legal representation is available? Does

the network persevere on individual cases? With a strong advocacy network, broad based policy implementation may be a "over time" process, but it will happen.

The Rest of the Story

The preceding discussion might lead one to believe that systems change in general, or systems change as specifically applied to education, is a fairly uncomplicated process. Nothing could be further from the truth. After 20 years of special education case law decisions, there are more fuzzy, unresolved questions than ever and assistive technology questions are adding to the pool of already complex issues. Examples of such questions include:

- How does one determine when assistive technology (like a computer) is needed for home use to provide an appropriate education? Is the decision different depending on the use of the technology, for example for print access versus instructional enrichment?

- How does one determine when assistive technology (like a wheelchair) is required to meet an educational need versus a medical need?

- How does one determine when assistive technology (like a reading machine) is required to meet educational needs rather than using human assistance (a person reader?)

- How does one determine when assistive technology must be provided on parochial school grounds?

- Is the equal access standard of Section 504 of the Rehabilitation Act and the Americans with Disabilities Act different from the appropriate standard of IDEA?

These and other unresolved issues will likely become clarified gradually through court decisions, administrative rulings and U.S. Department of Education policy interpretations. In the interim, states should view the lack of clarity as an opportunity to fill-in the gaps with policies and interpretations that support access to assistive technology. If assistive technology can become a priority agenda item for the special education policymakers and implementors in a state, the vision of access to assistive technology as needed for all students with disabilities becomes very real.

Diane Golden is Director with the Missouri Assistive Technology Project, Independence. FFI contact her at (816) 373-5193. For additional information or assistance regarding systems change activities in your state, contact your state's Tech Act project. For help identifying state Tech Act projects, contact RESNA Technology Assistance Project, 1700 N. Moore St., Suite 1540, Arlington. VA 22209 • (703) 524-6686.

Bringing Assistive Technology to Transition-Age Youth in Rural Minnesota

by J. Martin Carlson and Lisa Vervena

Around three quarters of Minnesota's population live in communities that fit within the federal definition of "rural." In these sparsely populated areas, transition-aged youth and young adults with developmental disabilities face all the typical challenges of maturing into adulthood, with the added challenge of access to only a limited range of assistive technology services where they live. Some parts of rural Minnesota are as much as six hours away from a metropolitan area containing the comprehensive custom services young people may need in order to regain, maintain or expand their functional abilities and avoid secondary medical conditions. This is a powerful reason to establish assistive technology outreach throughout the state.

Tamarack Habilitation Technologies, Inc., of St. Paul, has offered assistive technology services on an outreach basis in Minnesota since it was founded in 1990. In bringing services to people of all ages where they live - even in the most remote areas of the state - Tamarack technologists provide support in a manner that allows young people and their families to receive services without the inconvenience and in some cases hardship of traveling long distances. For teens and young adults this support plays a key role in their ability to progress and pursue their goals in three of the areas of life most important to this age group: attaining increasing independence, maintaining a social life outside the family, and preparing for a vocation.

For teens and young adults with disabilities, just as for their nondisabled peers, a top priority at this stage of life is achieving greater independence, which includes the ability to move at will throughout the community, the ability to make more of one's own decisions and carry them out, and the ability to communicate one's needs and desires. A second priority is maintaining a social life outside the family, which includes being able to take advantage of opportunities to spend time with peers apart from the presence of family and caregivers, and the ability to develop accepting relationships with peers. A third priority for transition-age young people is preparing for a vocation. This may include job training during high school and/or additional vocation-related education after high school. It may also include adaptations that help a young person obtain and perform a job.

Tamarack plays a role in making possible the pursuit of these goals by continuing through the years of transition to listen to the individual, family, and other caregivers as they express goals and expectations for the young person's independence, social life, and work life. We listen to their assessment of the barriers and solutions to overcome them. We hear preferences. We use discussion to distill the various functional challenges down to the most fundamental common denominators. That distillation process is critical to making the greatest functional progress with the least technology (and cost) burden.

For example, whatever their diagnosis, young people who are long-term wheelchair users usually have impairment levels that cause significant sitting and trunk instabilities. They lack much or all of the ability most of us have to voluntarily control our sitting postures/positions. Long-term spine collapse is a very frequent orthopedic complication. The other fundamental factor we need to appreciate is that effective hand, arm, and head control and stamina are directly linked to pelvic/spine/trunk stability and alignment. If, for instance, a young person's trunk is collapsing and the upper trunk and shoulders are listing and tilting toward the right, the consequences may be all of the following:

- The right elbow is employed as a prop and he/she loses trunk stability when trying to perform a right-handed function requiring elbow mobility. Reduced hand function has global consequences for the young person.

- The collapsing spine curvature may slowly (or rapidly is skeletal growth is not complete) increase and become more and more rigid.

- The rightward malalignment causes weight bearing to be concentrated on one side of the pelvis. This causes pain and could, in time, lead to skin break-down.

- The rightward lean of the upper trunk causes vertical head alignment to be a constant struggle, fatiguing, and perhaps even the source of neck and head pain.

- When the young person looks in the mirror and sees his/her head hanging off to one side, the person's sense of cosmetic compromise may affect social confidence. The off-center, non-vertical shoulder-neck-head alignment may even cause others to misjudge the severity or nature of the impairment, and affect social and vocational possibilities.

So, for the person who functions from a seated position, the structures and surfaces that provide postural support and stability have profound, global importance to health, independence, social development, education, and vocation. Orthotic and other forms of technological intervention, thoughtfully and skillfully rendered, can often be a means for minimizing secondary disabilities, medical complications, and limitations in the areas of autonomy, social connection, and vocational achievement.

The provision of assistive technology is a process, just as the transition from childhood to adulthood is a process. Since the necessity for technological intervention relates to specific medical diagnoses and solves problems impacting on health in either a specific or general sense, it is appropriate that the evaluation process be approved or initiated by the individual's medical doctor. The vast majority of assistive technology is funded through health insurance policies and programs. Payment is always dependent on physician prescription, and often is also dependent on rehabilitation professionals such as physical therapists, occupational therapists, and speech pathologists. The cost of custom assistive technology is difficult for insurance claim processors, case managers, and others to understand. The full cost of assistive technology is the very significant amount of time involved in evaluating, communicating, designing, trial and error, design refinement, documentation, and so forth. Once the process is completed and the item or system is provided, what one sees can be copied in a fraction of the total process time. It is the expense of fabrication that is the only cost easily recognized by most people not intimately familiar with the process. That leads to misunderstandings and prejudices, which add to already existing funding barriers.

Last year Tamarack had nearly 600 outreach service contacts with Minnesotans who have disabilities. In addition to direct service delivery to individuals of all ages who might otherwise have to do without appropriate assistive technology, Tamarack's outreach provides a valuable resource to communities. Forging links and developing partnerships with resources in different areas of the state in the form of workshops and inservices helps improve awareness of assistive technology options, funding resources that pay for those options, and the capability of local resources to deliver them. On a yearly basis Tamarack makes over a dozen presentations to parent organizations, educational agencies, health care providers, and employers to educate them about the availability of assistive technology and ways in which it can support young people with disabilities.

Many young people with developmental disabilities, particularly those with severe or multiple disabilities,

need a wide variety of assistive technology interventions. For those residing outside of metropolitan areas, this assistance may be very limited or unavailable without mobile outreach services such as Tamarack. The combined and collaborative approach in which Tamarack couples direct service provision with community education, holds the promise of offering Minnesota youth with developmental disabilities - wherever they live in the state - the greatest possible range of opportunities to grow into adults who lead satisfying and productive lives.

J. Martin Carlson is President and Lisa Vervena is a Rehabilitation Engineer with Tamarack Habilitation Technologies, Inc., St. Paul, MN. FFI call them at (612) 644-9950.

Advocating for Technology in MN: STAR

The STAR program (A System of Technology to Achieve Results) of Minnesota is working to increase awareness of and access to assistive technology devices and services through systems change and advocacy activities. Housed in the Minnesota Department of Administration in St. Paul, and funded by the National Institute on Disability and Rehabilitation Research, the program has six major objectives:

- STAR is committed to overcoming the obstacles of funding and availability that stand between assistive technology services and those who need them.

- STAR works to increase the involvement of people with disabilities and their families in decisions related to assistive technology. It provides information to support them in making informed individual decisions, and seeks to involve them in decision-making by policy-setting bodies.

- STAR works with state agencies to promote changes in policy and practice so that individuals continue to benefit from assistive devices and services as they move between home, school, work, and community.

- STAR works to change current policies that impede the availability of assistive devices and services, with special emphasis on state education, vocational rehabilitation, and medical assistance systems.

- STAR presents training programs and technology forums to ensure that providers of assistive technology have access to the latest information on assistive devices.

- STAR provides information and education to increase public understanding of the specific needs and potential for success that all individuals possess.

In the past year, STAR served over 5000 individuals with disabilities, family members, and professionals. Now in its sixth year, STAR continues its advocacy, education, information, and referral activities, supporting access to assistive technology for Minnesotans with disabilities.

Contributed by Rachel Wobschall, Executive Director, and Susan Asplund, Program Specialist, STAR. FFI call (612) 296-2771 / (612) 296-9478 (TDD).

Creating New Possibilities: Courage Center's Vocational Services Computer Program

by Jennifer Mundl

In 1991, Courage Center began its Vocational Services Computer Program to assist people with disabilities in using computers to meet their vocational and/or educational goals. The program began with one part-time employee and over a three year span grew to a staff of six, serving approximately 150 people annually. Today, it is a comprehensive program consisting of services for assessment, computer skills training, keyboarding, and a data entry employment option.

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Although the program serves people with a wide range of disabilities, many of the individuals who participate in the program have developmental disabilities associated with cerebral palsy or other disabilities.

Before an individual begins the program, he or she will meet with a staff member for a thorough intake evaluation. At this meeting, the individual and the program manager discuss vocational and educational goals as well as previous computer experience, any difficulties in operating a computer, work experience, educational goals, and areas of interest. Next, the program manager and computer specialist meet to discuss the information and design an assessment plan. Also, background information sent by the referral source is reviewed.

The next step is the actual computer assessment. This normally lasts one week over two different sessions. Common goals of the assessment include evaluation of an individual's current skills and how they relate to the job market or personal needs, potential to learn new computer skills, assessment of appropriate adaptive devices or access strategies, and career exploration. To meet these goals, a variety of methods are used to evaluate and assess including computerized tests, experimentation, training, observation, and exploration. After completing the assessment, an extensive report is written by the computer specialist with recommendations revolving around appropriate products and/or services necessary for an individual to independently operate a computer. The individual, referral source, computer specialist, and other interested parties then meet to discuss the assessment and results as well as plan the next steps in applying a computer to meet individual's needs.

Many individuals, at this point, enter into the computer

skills training or keyboarding training. The computer skills training is taught by qualified trainers in an one-to-one student-trainer ratio. Each program is customized to the individual's vocational and educational goals with specialized lessons in all areas of computer application. Common areas of study include word processing, graphic design, basic literacy, and spreadsheet and database applications. The program's length is based on the person's individual needs and averages from one to four months. After completion, each individual receives a certificate signed by the computer specialist and trainer stating the computer skills learned.

The keyboarding course is a self-paced program with a staff person providing guidance. Participants work on keyboarding skills, with a focus on learning standard or adaptive typing procedures and fingering for one or two-handed typing.

Another exciting program of Courage Center Vocational Services Computer Program is Data Ability. This is an employment choice for individuals and is designed to be a

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> The accomplishments of this program are greater than...anticipated when it began three years ago.

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stepping stone to community employment. Individuals are employed by Courage Center, which contracts with various companies. Participants perform data entry such as updating mailing listings and customer information. Each person is paid on a per piece basis. There is staff support available for assistance in manipulating work material, set-up, problem-solving and other similar work needs.

The accomplishments of this program are greater than would have been anticipated when it began three years ago. Its successes can be credited primarily to the highly motivated participants, as well as to the dedicated staff. It is the participants who make the effort worth everything! The smiles, laughter, and personal growth are rewarding and exciting to witness. As computers rapidly continue to be integrated in to work, school, and home environments, we expect that the computer program will continue to grow and give new chances and options to people who once had few.

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Beating the Odds: Jay and Dennis

The unemployment rate of people with disabilities is alarming, having reached in excess of 65%. This proportion is even higher when dealing with persons with severe or multiple disabilities affecting physical, cognitive, and visual abilities. Jay Metcalf and Dennis Wekwert were born with cerebral palsy with limitations in many areas that affect their ability to work independently. They both use an electric wheelchair, augmentative communication device, switches, computer adaptations, and other adaptive products. And Jay and Dennis are two individuals who have beaten the odds and found successful employment with the assistance of the Courage Center Vocational Computer Program.

The first step in accomplishing their goal of employment was completion of a vocational computer assessment. It identified an effective method of computer access, evaluated their current computer skills, assessed

> The unemployment rate of people with disabilities is alarming, having reached in excess of 65%.

aptitude to learn new skills, and explored ways a computer could be useful on-the-job. A variety of keyboards, switches, scanning programs, efficiency software and mounting devices were tested, and aptitude and potential skills were evaluated through the use of standard and specialized software. After the assessment, a meeting was held to discuss the results and make plans regarding the next steps to incorporate computers into Jay's and Dennis' personal lives.

Jay and Dennis enrolled in Courage Center's Skills Training Program. All computer equipment and necessary adaptations were provided and their trainers were highly qualified in teaching concepts to people with disabilities. As students, they were required to attend the Computer Program three to five times a week for individualized instruction and practice time for homework assignments. They received one-to-one instruction in basic literacy, word processing, database applications, spreadsheet usage, and adaptive keyboard strategies. After completing this process, Jay and Dennis received a certificate of accomplishment and were now ready to find work.

Finding appropriate employment was no easy task. Much research went into what accommodations and options were currently available for Jay and Dennis. To meet their needs, an enclave was established at Courage Center where several individuals would work together to perform data entry. The enclave was initiated in March of 1993 and was made possible through a partnership with

Dakota Inc., a day training and rehabilitation provider. Contracts from Minnesota Golf Shows and Field of Dreams were obtained in which the group was responsible for updating client lists and information. Each person was a Courage Center employee and earned a paycheck based on the amount of work completed. Individually, the group would not have been able to finish the projects, but together they have proven that the team approach works.

Today, Jay, who has severe physical disabilities affecting speech and dexterity, utilizes a joystick with his chin for entering information into the computer. He accomplishes this with scanning software that systematically highlights the alphabet and other necessary keyboard keys. When the desired key is highlighted, Jay presses the joystick and a selection is made. Through this technique, he is able to utilize any software and perform any task that someone who can type on a standard keyboard could do. Furthermore, he recently purchased a laptop computer with special software and hardware that allows him to speak through a synthesized voice. He is now quite verbal and expresses a wonderful sense of humor. He comes to Courage Center Data Ability Program every afternoon

> Jay and Dennis are two individuals who have beaten the odds and found successful employment...

where he works on an IBM computer entering mailing labels with three other individuals, his accuracy and speed continuing to improve.

Dennis has always wanted to work, but could never find a job that was satisfying and rewarding. He is independent in his work and uses a small keyboard with one hand. Single-key typing and keyboard shortcuts allow him to manipulate the computer more effectively. He is performing data entry for the same companies as Jay. His first purchase from his earnings was a VCR and now he is saving for his own computer system. He has grown tremendously and has even began public speaking on behalf of Data Ability using his Touch Talker.

The accomplishments of Jay and Dennis seem overwhelming. No one could have ever anticipated where they would be today. They are wonderful and dedicated employees who take pride in their accomplishments. They have benefited from Courage Center and Courage Center from them. They are perfect examples of what is achievable through computer technology.

Contributed by Jennifer Mundl, Courage Center.

AgrAbility: Cultivating Independence Through Rural Partnerships

by Randall L. Rutta

The majority of people engaged in farming, ranching, and farm work, and their families, want to remain in agriculture. It is more than a livelihood to them; it is a way of life. For many, their connection to the land goes back generations. However, the presence of a disability can seem to mean the end of this legacy. Rural isolation, limited financial resources, and inadequate access to services and expertise frequently prevent farming families from accommodating the disability of a family member. Whether that disability is a developmental disability appearing in childhood or a disability occurring in adulthood as a result of accident or illness, it often seems to mean the end of the individual's life in agricultural production.

By the mid-1980s considerable expertise was becoming available for the adjustment of agricultural operations to safely accommodate disability, including the adaptation and modification of farm equipment, buildings, and operations. For two decades, the Vermont Rural and Farm Family Vocational Rehabilitation Program had engaged Vermont's State Vocational Rehabilitation and Cooperative Extension Service programs in assisting farm families affected by disability to continue in farming. Purdue University's Breaking New Ground Resource Center was emerging as a national and international resource in applying rehabilitation engineering and related expertise to solving disability-related challenges in agricultural production.

In 1986, the Iowa Easter Seal Society established the Farm Family Rehabilitation Management (FaRM) to assist Iowa farm families affected by disability. This highly successful program was identified by the National Easter Seal Society as a model program ideally-suited for replication by other Easter Seal affiliates seeking to expand services to rural residents with disabilities.

The national society soon realized that the funding needed to start innovative rural programs was generally limited. Given the merits of the programs, however, the national society believed that core federal support might be made available to expedite the implementation and expansion of program assisting farm, ranch, and farm worker families affected by disabilities. In 1990, Easter Seals recommended that Congress authorize a new program at the U.S. Department of Agriculture that would fund education and assistance for farmers with disabilities and their families by linking cooperative Extension Service agencies with nonprofit disability service providers. A provision was included by Congress in the 1990 Farm Bill that authorized the AgrAbility Project.

The AgrAbility Project provides guidance on safely accommodating disability in agricultural production. It succeeds by engaging Extension Service agents, disability experts, rural professionals, and volunteers in offering an array of services, including providing on-the-farm technical assistance in adapting and using farm equipment and tools; modifying farm operations and buildings; providing agriculture-based education to prevent further injury and disability; exploring creative options for meaningful, well-paid employment in agriculture, such as supported work; and upgrading the skills of Extension Service agents, rural health and rehabilitation personnel, and others in assisting people with disabilities to succeed in farming. In addition, supports farm families through, for instance, facilitating the integration of children with developmental disabilities into mainstream rural activities such as 4-H and Future Farmers of America.

In many cases, AgrAbility provides expert guidance, with the actual cost of adaptations minimized by the use of donated materials and skilled labor. Vocational rehabilitation, the state mental retardation/developmental agencies, and private insurance programs pay for a significant share of accommodations recommended by AgrAbility staff. These programs realize the benefits of having knowledgeable AgrAbility project staff conduct assessments, propose workable solutions, and otherwise assist in facilitating the accommodation of disability in agricultural worksites, operations, and home environments. The scope and effectiveness of AgrAbility assistance is further increased by contributions of businesses, commodity groups, social organizations, and others. Farm Bureaus, Land O' Lakes Corporation, and Kraft Dairy Foundation are among AgrAbility's active supporters.

The AgrAbility Project has emerged as a powerful force in rural America. Currently, 17 AgrAbility projects serve 19 states: Colorado, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Michigan, Minnesota, Missouri, Montana, New Hampshire, New York, North Carolina, North Dakota, South Carolina, Tennessee, Vermont, and Wisconsin. The intent and experience of the AgrAbility Project will be revisited by Congress in 1995 as it begins the process of reauthorizing the Farm Bill and evaluating federal agricultural programs. The National Easter Seal Society will advocate for continuing federal support for the project because it is an effective, cost-efficient means of maximizing scarce rural resources on behalf of our agricultural community affected by disability.

Randall L. Rutta is Vice President of Government Relations, National Easter Seal Society, Washington, D.C. FFI contact him at (202) 347-3066.

Recreation: Turning Dreams Into Reality in Utah

by Marilyn Hammond

Recreation makes life more rewarding, challenging, and healthy. Everyone deserves the opportunity to pursue their interests and dreams through recreation and leisure. However, the importance and benefits of recreation for persons with disabilities have been relatively neglected until recently. As a result, individuals with disabilities, family members, and professionals may not be aware of the many kinds of recreational organizations and assistive technologies now available. Recreational assistive technology has the potential to turn dreams of skiing, bicycle riding, horseback riding, and playing games into reality.

The Utah Assistive Technology Program (UATP) is one of the Tech Act states funded by the National Institute on Disability and Rehabilitation Research. Located at the Center for Persons with Disabilities at Utah State University, the UATP has produced a videotape about recreation for people with disabilities. The video, entitled *The Sky's the Limit* is designed to motivate and encourage parents, professionals, and individuals with disabilities to participate in recreation. This positive video focuses on people's abilities as demonstrated through hang gliding, horseback riding, water and snow skiing, hiking, bicycle riding, tennis, and basketball. Another videotape, *Toys for All Children*, discusses the many available commercial toys and easy adaptations to enhance play for children with disabilities. The video includes a resource guide that lists toy catalogs, books, videotapes, and libraries. The UATP has also compiled an extensive national list of recreational organizations for individuals with disabilities.

Direct services, including recreation, are provided to individuals with disabilities through UATP subcontracts and other grants with Independent Living Centers across the state. Two of these programs are Common Ground Outdoor Adventure and Active Re-Entry.

Common Ground Outdoor Adventure offers outdoor opportunities for people of all abilities. The purpose of the program is to integrate people with and without disabilities, promote an understanding and appreciation of the natural environment, and discover new ways to access the outdoors. In addition, it is hoped these outdoor adventure experiences, which include canoeing, camping, hiking, rafting, dog sledding, and skiing, will reduce stereotypes, raise awareness, and empower people to realize their full potential.

Common Ground also works in conjunction with Bridgerland Audubon Society, Utah State University (USU) Outdoor Recreation Center, and the local Forest Service office in an effort to promote integration and program

> Recreational assistive technology has the potential to turn dreams of skiing, bicycle riding, horseback riding, and playing games into reality.

adaptation. For instance, Common Ground and UATP are purchasing adapted cross country and downhill ski equipment, including sit skis, a bi-ski, a mono-ski, and outriggers. The sit ski is similar to a sled with metal edges. The bi-ski is a bucket seat mounted on two skis with a suspension system. A mono-ski has a seat mounted on a single ski for people with strong upper body mobility. Outriggers are adapted ski poles with small skis attached for stability and balance. Equipment will be used for downhill and cross country ski trips with trained volunteers every other week, and will be available for rent at other times through the USU Outdoor Rec Center.

One of the activities of Active Re-Entry is sharing accessibility information. Resorts, recreational centers, stadiums, playgrounds and parks should be accessible to everyone. People with disabilities deserve an equal opportunity to participate in sports and recreational activities and enjoy the natural beauty of our local and national parks. However, parks and campgrounds that are identified as being accessible may not necessarily be so. The inconsistent standards and lack of available information frustrated Lisa Perla and Terry Gibbs of Active Re-Entry, so they decided to publish an outdoor accessible recreation guide to eastern Utah. Funding was obtained from the Utah Governor's Council for People with Disabilities. A standardized checklist was developed and each recreation site was evaluated. Coordination with local park officials resulted in an exchange of information about projected plans and needed accessibility changes. Active Re-Entry is also involved in river trips, cross-country skiing, bowling, and several other activities.

One of the reasons people may live in Utah is to partake of the many recreational opportunities. For that reason the UATP works with Independent Living Centers in Utah, and organizations such as S'PLORE, the National Ability Center, Neptune Divers, and the Intermountain Health Care Wheelchair Sports Foundation help ensure that most, if not all of the recreational opportunities are available for persons with disabilities. Nearly any sport can be adapted with the right equipment, accessible facilities, and motivated participants. Recreational activities can open up a lifetime of positive and rewarding experiences for children and adults with disabilities.

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Assistive Technology and the Mo. to Community Living

by Laurel S. Mendelson

Many people with developmental disabilities have functional limitations in mobility, communication or activities of daily living. Until recently, impairments in one or more of these areas precluded community living. Individuals were placed in nursing facilities - not because they required ongoing *medical* care, but because they needed high levels of *personal* care throughout the day. Even in cases where assistive devices might have significantly increased independence, there were few opportunities for nursing home residents to obtain equipment or move into the community.

This situation began to change in 1987 with the passage of the Nursing Home Reform Act (OBRA-87, PL 100-203). This legislation mandates that every nursing facility receiving federal funds perform an annual review of all patients to determine whether they require the level of services provided. It further mandates that individuals with developmental disabilities who do not need skilled nursing care, but who do need support or specialized services, be given the choice to move to a more appropriate residence.

The OBRA legislation has had a direct impact on the approximately 52,000 individuals with mental retardation living in nursing homes throughout the nation. By the time the regulations are fully implemented, at least 20,000 people will have moved into independent or group residences.

Each state is responsible for providing the services necessary to support community living. In response to the federal requirements, the Illinois Legislature passed the Community Integrated Living Arrangements (CILA) Licensure and Certification Act (PL 86-922) in 1988. This legislation promotes the licensure of community agencies to provide an array of services for people with developmental disabilities. According to the CILA guidelines, individuals work with case managers to choose the residential supports, employment, health care, social services, education, and recreational activities that best meet their needs.

But legislation alone has not been sufficient to bring about statewide change. Concurrent with the passage of the CILA Act, a class action suit. Bogard v. Bradley, was filed against five agencies in the name of nearly 3200 nursing home residents with developmental disabilities. The suit claimed that the State of Illinois discriminated against this population and failed to provide them with appropriate placements and services. Only after the case was settled in 1993 did the services promised by the CILA legislation truly become available. Among the results of the consent decree settlement were guarantees that the class members would have access to necessary evaluations, adaptive equipment, and community residential placements if they choose to leave their nursing facilities.

The Assistive Technology Unit (ATU) at the University of Illinois at Chicago currently receives more than 200 referrals a year for equipment to facilitate the move into community residences. The unit, a department in the Institute on Disability and Human Development, receives requests for evaluations in the areas of seating and mobility, communication, activities of daily living, environmental control, work-site access, and home access. Evaluations are performed by teams of rehabilitation engineers, physical therapists, occupational therapists, and speech pathologists. Funding for most of the recommendations is pursued through the Illinois Department of Public Aid.

Initial assistive technology evaluations generally occur while an individual still resides in the nursing home. Recommendations in this setting involve equipment that is necessary for the individual to move out of the facility, including wheelchairs and seating systems, devices to assist with basic self-care activities such as feeding and dressing, and strategies for rudimentary communication. Once in a community residence, both experiences and needs change. Homes must be adapted to allow wheelchair access and to maximize independent function. Skills must be cultivated in the areas of telephone usage, meal preparation, money management, and job tasks. Social and recreational pursuits must be developed. Because the new community residents have so many new opportunities, their need for assistive devices must be re-evaluated: it is possible that some individuals will require additional adaptive skills or equipment for every new experience they encounter.

The process of providing adaptive equipment to this population provides a rich opportunity for studying the benefits of assistive technology in community integration. Over the next several years, hundreds of nursing home residents will both receive assistive technology and move to community residences. The interrelation of these two experiences is being studied at UIC's Institute on Disability and Human Development. Currently in the second year of a five-year longitudinal study funded through a subcontract with the University of Minnesota's Research and Training Center on Residential Services and Community Living, researchers are monitoring this population from the time they are determined to be CILA-eligible until they live in the community with all necessary adaptive equipment. The study will examine individual outcomes as well as system-wide opportunities that arise from assistive technology application. Changes in vocational opportunities, recreational and social activities, community support services, health care needs, and living environments will be correlated to both moving and to specific technology. Results will be

analyzed based on individuals' diagnoses, impairments, ages, and ethnic backgrounds.

It is clear that assistive technology can significantly increase the independence of people with disabilities. In many cases, adaptive equipment can be the determinant for deciding between residential or community placement. This in turn can make the difference between segregation and full community integration.

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Returning to the Community: Melvin's Story

The benefits that can be achieved from assistive technology in the transition from nursing home to community residence are evident in the story of Melvin, a 52-year-old man with cerebral palsy and mild mental retardation. He is unable to walk and has only limited use of his upper extremities, thus he is dependent on others for most of his daily care. Melvin has difficulty articulating words clearly, but he cheerfully manages to make himself understood.

Melvin grew up in a close family of seven siblings. All of his family took part in his care, but his primary caregiver was his mother, who pushed his wheelchair, put him to bed, and bathed and toileted him. Melvin lived with his mother until she died from a heart attack in 1985. After her death, Melvin lived for a short time with one of his brothers, but after less than a year the brother became ill and Melvin had no choice but to move into a nursing home.

In the nursing home, Melvin's independence was severely curtailed. He didn't like the food and he couldn't shower or use the toilet when he chose. He had friends in the nursing home, but there was not much for them to do. There was no one to push Melvin's wheelchair, so he spent a lot of time sitting in the day-room or the hallway. After a few years his wheelchair broke, and rather than pursue proper replacement, the nursing home loaned him one that didn't fit him particularly well. In the nursing home, independent mobility was not encouraged and as a result Melvin's upper extremity function decreased so that he could no longer feed himself or turn on his radio. Melvin didn't like life in the nursing home, but he "had to deal with it," since he had no place else to go.

In 1991, Melvin was selected for the CILA program. His case worker immediately began to look for a group home that could accommodate him. In preparation for community placement, Melvin was referred to the Assistive Technology Unit at the University of Illinois at Chicago for seating and wheeled mobility, augmentative communication, environmental controls, and any other equipment that might increase his independence.

Melvin was first evaluated for a new wheelchair. He was not able to propel a manual wheelchair or operate a standard joystick, so clinicians evaluated him for head control of a power wheelchair. Melvin was so successful using this type of controller that a RIM controlled wheelchair was ordered for him. Along with the head controller, the wheelchair had the capacity to accept an environmental control board; this would be beneficial if he ever wanted to use a communication device.

With the arrival of his new wheelchair, Melvin felt much more optimistic. He was no longer dependent on others to move him around and he didn't have to sit in one place all day long. He was then evaluated for any other equipment that would help increase his independence. In the spring of 1994, Melvin received a plate guard and feeding platform to allow him to return to feeding himself and a toilet safety frame so that he could take care of his toileting needs without assistance. He also received environmental controls that let him control lights, his radio, a television, and a fan, but he chose not to use these in the nursing home for fear that they would be stolen.

In October 1994, Melvin finally moved into his community residence. He lives with two other men and an aide who helps them with activities of daily living, shops and cooks, and provides transportation. Melvin loves his new home. He already feels ownership of the house and takes a lot of pride in paying his bills and his share of the rent. The best part of the new residence is the opportunity it offers for self-determination. Now, Melvin can visit his family whenever he wants. He can decide for himself whether to go to work or take off a day. If he wants to go to the park, baseball game or show, he goes by himself using his new wheelchair. He chooses what he wants to eat and feeds himself. He watches television and listens to the radio whenever he wants. But no one can sum up Melvin's new situation better than he himself. At his last visit to the Assistive Technology Unit, Melvin explained that now he really feels good about life now. "I can go anywhere," he told us, and "I can do anything."

Contributed by Laurel S. Mendelson, Institute on Disability and Human Development, University of Illinois at Chicago.

Aging and Assistive Technology: Improving Services to Older Adults

The need for and benefits from assistive technology extend across the life span of people with developmental disabilities. Programs such as the two described below are seeking to improve the capacity of service providers to make available a range of assistive technology options for the individuals with developmental disabilities whom they serve.

◼ Small Changes, Big Differences

The U.S. is growing older, both in total number of persons over age 65 and in the proportion they represent of the total population. In order to remain independent and age successfully, the aged population needs to be aware of, obtain, and utilize assistive technology devices and services. Often residents of rural areas or small communities, as well as those who find it difficult to leave their homes, are unaware of the wide array of available "convenience" devices. Even when they know of various devices, rarely do they have the opportunity to see or try-out these products. Community-level service providers need to increase their capacity to deliver appropriate and accessible services and programs to elderly people.

"small changes...BIG DIFFERENCES" (SCBD) is a program developed by the Iowa Program for Assistive Technology (ITAP) to address this need in Iowa. Funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, SCBD enhances the capacity of local communities to increase the awareness and acceptance of assistive technology. The ITAP has provided an awareness kit, a train-the-trainer workshop, and resource materials free of charge to each county office of the Area Agencies on Aging (AAA), regional agencies providing services in the state of Iowa. The self-contained awareness kit and training provide the program materials necessary to carry out a variety of community awareness programs. Each kit contains 22 low-tech assistive devices, slide and video programs, a flipchart, a poster, elder brochures, catalogs, and other support materials. Each office receives a large supply of the Independent Living Series brochures, which focus on the benefits of assistive technology for elderly people. The assistive technology products in this kit were selected because they offer a sampling of items for a variety of activities of daily living, they are low cost, simple, attractive, and useful to a great number of people.

The local AAA arranges the training location and identifies the workshop audience. A typical audience includes AAA staff and community elder volunteers. In addition, the AAA might invite nursing home staff, public health nurses, homemaker/home health aide supervisors, case managers, and hospital discharge planners. The two to three hour training provided by Iowa Program for Assistive Technology staff shows local volunteers and staff how to use the kit materials to provide community awareness programs. Each assistive technology device is demonstrated and its potential benefits to elderly people explained. The participants then identify who in their community needs this information: elderly, homebound elderly, their families, all service providers, and persons who interact with elderly people. Next, the group identifies where the program needs to go specifically in their community to get to each audience and in what format: table top display, brief presentation, mailing or passing out of brochures, or articles. This becomes their action plan. As part of the training, participants are made aware of other services and supports also available through the Iowa Program for Assistive Technology. Many of the AAA offices have made unique variations or additions to the original kits. Some have included homemade devices and demonstration models. Others have created local loan closets or low interest loans. Several allow the kits to be used by other agencies for programs or home visits.

"small changes...BIG DIFFERENCES" goes a long way in fulfilling one of the primary missions of the State Technology Grants. By training individuals in local communities and providing them with the tools they need, SCBD encourages increased awareness and acceptance of assistive technology.

Contributed by Jane Gay, Program Specialist for the Iowa Program for Assistive Technology, Iowa City. FFI contact her at (319) 356-4463.

◼ Research and Interventions

The Center for Assistive Technology (CAT) at the University at Buffalo is dedicated to conducting research, development, education, and service programs on assistive technology in collaboration with consumers, researchers, and agencies. The CAT's programs address the functional needs of persons with all types of disabilities. With over 100 full and part-time professional staff, all relevant disciplines are represented, including occupational, physical and speech therapy; mechanical, electronic and biomedical engineering; rehabilitation and geriatric nursing and medicine; architecture and design; business marke..ng and

law; social sciences; and vocational rehabilitation. The staff, in turn, have strong affiliations with consumer organizations and service providers nationwide. Collectively, team members assess the value of assistive technology and environmental modifications across the age range, from toddlers and seniors.

One program of the CAT is the National Rehabilitation Engineering Research Center on Assistive Technology and Environmental Interventions for Older Persons (RERC). The RERC was funded in 1991 on a five-year cycle by the National Institute on Disability and Rehabilitation Research. This center is investigating how assistive devices and home modifications help maintain a person's independence, or at least reduce the amount of care required, as they and their care providers age. Although the center is addressing the needs of all older persons - those aging with and those aging into disabilities - a specific project focuses on older persons with developmental disabilities.

Older persons with developmental disabilities have had disabilities since childhood. Yet they also must cope with the gradual onset of functional impairments, and the chronic and acute diseases of aging. Persons with developmental disabilities have specific needs and sometimes unique applications for assistive devices. Service providers should understand the interaction of aging and developmental disabilities to provide the most effective interventions for maximizing independence and quality of life. Unfortunately, there are limited resources to provide training and awareness in this area.

In response, the RERC on Older Persons has developed a workshop program that is available nationwide. The workshop's paper and video materials draw upon the expertise of multiple disciplines in a curriculum designed to provide useful information to direct care service providers. Workshop participants identify and analyze problems as presented in audio/video case studies, then select from among available technology and environmental options to meet an individual's specific needs. The current information on technology, resources, and agencies is supplemented by group discussions focused on the problem and solution exercises in the case studies. The workshop can be scheduled as either a half or full day presentation, while some of the case materials are available from the CAT through the publications catalog of the Center on Assistive Technology.

Contributed by Joseph P. Lane, Director, Rehabilitation Engineering Research Center, University at Buffalo, Buffalo, NY. FFI contact the Center at (800) 628-2281 (Voice/TDD) or (716) 829-3141 (voice).

Assistive Technology Resources: Organizations

- **Alliance for Technology Access.** 2173 E. Francisco. Blvd., Ste. L, San Rafael, CA 94901 • (415) 455-4575. An organization of resource centers serving children and adults with disabilities across the country in exploring assistive technology. The Alliance can refer individuals to the resource center in their area.

- **Assistive Technology Funding and Systems Change Project.** Susan Goodman, Project Director, Assistive Technology Funding and Systems Change Project, United Cerebral Palsy Associations, 1522 K St., NW, Suite 1112, Washington, DC 20005. Voice/TT: (202) 842-1266. Provides information on this newly-established project that offers nationwide training, technical assistance, and materials related to assistive technology funding and systems change.

- **Closing the Gap.** P.O. Box 68, Henderson, MN 56044 • (612) 248-3294. Sponsors annual international conference on microcomputer technology in special education and rehabilitation; also publishes newsletter exploring uses of microcomputers as personal and educational tools for people with disabilities.

- **Center for Special Education Technology.** The Council for Exceptional Children, 1920 Association Dr., Reston. VA 22091 • (800) 873-8255. Collects and disseminates information about using technology in the education of children and youth with disabilities.

- **National Rehabilitation Information Center (NARIC).** 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319 • (800) 34-NARIC. Provides information on disability and rehabilitation-related issues.

- **RESNA Technology Assistance Project** . 1700 N. Moore St., Suite 1540, Arlington. VA 22209 • (703) 524-6686. Provides information on Tech Act activities in all states.

- **Technical Assistance for Parent Programs (TAPP) Project.** Federation for Children with Special Needs. 95 Berkeley St., Ste. 104, Boston. MA 02116 • (617) 482-2915 (Voice/TDD). Provides technical assistance for federally-funded Parent Training and Information Centers, which make parent-to-parent training and information services available to parents of children with disabilities across the country. The project will refer parents and other interested persons to the Parent Training and Information Center in their area.

out – wanted out of the institution – forever. When we first met, I talked to Kathy using my manual communication board, and she took a keen interest in it. Later, as we were leaving, I spoke to her using my Liberator. It was then we learned of her interest in obtaining a similar device. When I told her that the law said she should get what she needs, Kathy cried inconsolably and with good reason. For Kathy is very much like many others we all know: the greatest handicap she faces is not her disabilities, but others' severe ignorance and profound under-estimation of her abilities. Having access to supports, like personal assistance and assistive technology, is critical. In fact, for individuals like Kathy and myself, it's often the only thing that can begin to tear down the age old walls of myths and stereotypes regarding people with disabilities.

The good news for Kathy is that she moved out of the institution and into a group home, which, while not perfect, is a beginning. Kathy, the last I heard though, still has not gotten the communication device and any of the ongoing support and training she would need to learn how to use it. Like millions of other Americans with significant disabilities, Kathy has a strange attraction to proverbial monkey wrenches, and, what I call plain inertia. The inertia is not on her own part, but is systems inertia – the lack of urgency and sustained efforts on the rest of our parts.

You know, we all talk a good game about the power and the potential of assistive technology. And, it is all very true. But, I am increasingly seeing, both as an individual and a federal executive responsible for leading a national network committed to systems change, that where the real rubber meets the information highway is in transforming that power and potential into everyday realities in peoples lives!

Creating true access to assistive technology means much more than creating access to devices – to hardware and software. Much more significantly, it means building in training, building in ongoing support, and building in opportunities for self-instruction and trouble-shooting, both for the individual relying on the device and his/her partners or assistants. This is especially true for the kind of technologies on which I rely most. But it is also true for a great many other assistive devices and technology solutions that are being used in school and work situations, in particular.

Now that I run a $109 million dollar federal agency, I have a great many more challenges to address in this regard. However, unlike the vast majority of Americans with significant disabilities and their families, I also have a great many more resources and accommodations at my ready disposal to organize and deploy as I see fit. Recently, for instance, I got a new custom-made desk, which I can raise and lower with the push of a button, and which is designed to enable me to stand while working for part of the day, thus reducing my chance for both fatigue and other possible secondary disabilities. Some might see this as a luxury. I

think not. My staff reports that the only down side to it is that as my lung capacity increases, my bark will be louder than ever. Hopefully, that will make my occasional bite pale in comparison.

Increasingly, I am also relying on my Liberator, not just for communication, b   as my principal management tool. With it, I am able to access my computer, e-mail, and Internet; the reason that I am able to do this is the ongoing support I am able to draw on. I have a staff person, Ron Filewich, who is my trouble-shooter on technology. This was one of the best management decisions I made early on at the Administration on Developmental Disabilities. On average, Ron now spends over a third of his time trouble-shooting, developing macros, making sure everything is backed up – not just with respect to the Liberator, but with regard to the Local Area Network (LAN) and Internet as well. He, in turn, has an entire network, inside and outside of the government, backing him up. He is there to anticipate problems and solve glitches as soon as they occur because, frankly, I cannot afford slow downs or to be non-productive – not for five minutes, a half hour, nor, certainly, an entire day.

What is even more important, is that America can no longer afford it either. America can no longer afford to have a few exceptions to the rules, like myself, hanging around. Right now there is really just a relatively small number of us who are exceptions to some extremely important rules. We are exceptions in that we have had access not simply to assistive technology, but to the training and, most importantly, to the ongoing support we need to make it work to not just improve our own lives, but to make a critical difference in the lives of our families, communities, and our nation.

The challenge that you and I face, therefore, is not to come up with a few more exceptions, but to change the rules of the game entirely. As President Clinton says, America cannot afford to waste any of its citizens. What does this mean in practice? It means figuring out the best ways to get ongoing technology training, assistance, and support to individuals. It means educating individuals and their families about their rights under the Individuals with Disabilities Education Act (IDEA) and the most recent rehabilitation amendments – and making these laws work for people. It also means doing a great deal differently from what we typically have done in the past – reaching out and reaching beyond the traditional ways of thinking about and responding to the challenges and opportunities presented by disability in the coming 21st century.

The disability community must work with those of us in the Clinton Administration to infuse universal access as a pivotal element in the National Information Infrastructure. We must work to infuse access to assistive devices and technology solutions and the ongoing training and support it takes to master their power as a central practicing tenet in each and every one of President Clinton's major new investment initiatives – in Head Start, in Health Reform and Personal Assistance, in National Service, in Goals 2000, in

the School to Work Initiative, in Welfare Reform, and in the Empowerment Zones. By seizing on and influencing these ventures, you and I have an opportunity, and a much stronger obligation, of a lifetime.

Our nation simply can no longer afford, either in the rawest human or economic terms, to continue to spend between two and three hundred billion dollars a year keeping Americans with disabilities economically disenfranchised and, for the most part, needlessly dependent. There is a better way, and that way begins with working with young Americans, both those with and without disabilities, and especially with those who are left out and left behind – those at the very margins of the American community. It begins with preparing an increasing number of these young men and women to come together to form what might be

called a National Human Support Infrastructure, which would offer individuals with significant disabilities of every age and background ready access to the same kind of on-going training, technology support and trouble shooting that I now take full advantage of myself. You can be certain that we in the Administration on Developmental Disabilities and elsewhere throughout the Clinton Administration will be working to this end. I challenge you to work with us to do the same!

Bob Williams is Commissioner of the Administration on Developmental Disabilities, U.S. Department of Health and Human Services. This article was adapted from his Keynote Address to the RESNA Conference in Nashville, Tennessee, June 1994.

Assistive Technology Resources: Print and Media Materials

- **Assistive Technology News.** 19 Crescent Court, Sterling, VA 20164 • (703) 406-7831 (Voice/TT). A newspaper that informs and updates employers on the Americans with Disabilities Act and ways to comply with the act through assistive technology.

- **Assistive Technology Resource Directory** (1990). The Center for Special Education Technology, The Council for Exceptional Children, 1920 Association Dr., Reston, VA 22091 • (703) 620-3660 / (800) 873-8255. An annotated directory of resources to meet the need for information and awareness of assistive technology resources.

- **Assistive Technology Sourcebook** (1990) and **Assistive Technology: A Funding Workbook** (1991). RESNA Press, 1101 Connecticut Ave. NW, Ste. 700, Washington. DC 20036-4303 • (202) 857-1199. Guides to assistive technology, including information resources, equipment evaluation, personal care, education, employment, recreation, mobility, computer access, and funding.

- **A.T. Quarterly.** RESNA Technical Assistance Project. 1700 N. Moore St. Suite 1540, Arlington, VA 22209-1903 • (703) 524-6686 (voice) / (703) 524-6639 (TT). A newsletter containing information about the legislative and adoption aspects of assistive technology.

- **Communication Outlook.** Artificial Language Lab. Michigan State University, 405 Computer Center, East Lansing, MI 48823 • (517) 353-0870. A newsletter covering newest developments in applications of

technology to the needs of those with communication impairments due to neurological/neuromuscular conditions.

- **Direct Link.** C-CAD at Infomart, 1950 Stemmons Freeway, Ste. 4041, Dallas. TX 75207 • (214) 746-4217. A quarterly publication of C-CAD, a project to enhance quality of life and employment options of people with disabilities through use of modified personal computers, adaptive devices, custom software.

- **Journal of Special Education Technology.** Peabody College of Vanderbilt University. Box 328, Nashville, TN 37203 • (615) 322-8150. A quarterly journal containing information, research, and reports of innovative practices in the application of educational technology to the education of exceptional children.

- **Technology and Disability.** Center for Assistive Technology. 515 Kimball Tower, SUNY at Buffalo. Buffalo, NY 14214 • (617) 928-2617. A peer-reviewed periodical that deals with the application of rehabilitative and assistive technology for persons with disabilities, particularly in the performance of major life functions: education, employment, and recreation.

- **VoRTECHS.** Center for Rehabilitation Technology Services, 1410-C Boston Ave., P.O. Box 15, West Columbia, SC 29171-0015 • (803) 822-5362 (voice/TT). A newsletter providing information on issues related to the use of assistive technology in vocational rehabilitation agencies.

In this issue . . .

- Assistive Technology and National Policy

- Assistive Technology Programs Serving Children and Families

- Assistive Technology Programs for Transition and Employment

- Assistive Technology Programs in Education

- Assistive Technology Programs Supporting Community Living

- Assistive Technology and Aging

- Assistive Technology Organizations and Publications