A Review of **AT** Successes and Barriers
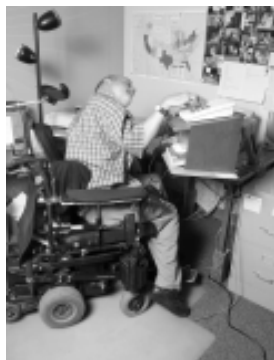
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Is it working?

A Review of AT Successes and Barriers

Tanis M. Doe

Is it working?

A Review of AT Successes and Barriers

Tanis M. Doe, Ph.D., *Editor*

A publication of the
Community Research for
Assistive Technology Project

California Foundation for Independent Living Centers (CFILC)
is a professional trade organization that provides support to 29 Independent
Living Centers statewide. For further information or assistance, please
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Patricia Yeager, Executive Director

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PREFACE

Steven James Tingus, Disability Policy Leader and Advocate

> *"Federally-funded research has helped encourage and educate policymakers to envision and design a society that is universally accessible and functional for all people in every stage of life. As a result, it is now possible for people with significant disabilities to live full and fulfilled lives. It is already commonplace to find people who are blind using computers, people who are deaf attending the theater, and people in wheelchairs traveling in planes and driving their own cars. The future holds even more promise."* (NIDRR Brochure 2000 published on the WWW http://www.ncddr.org/new/announcements/nidrr_brochure.html)

As research topics, Assistive Technology and its effectiveness clearly fit into the NIDRR long-range plan. They relate to Independent Living by evaluating the effectiveness of current and evolving AT through evidence-based research. The Community Research for Assistive Technology will look at AT's usefulness, applicability, and funding from the perspective of consumers. The project evaluates current use and the need to get appropriate AT into the hands of people with disabilities so they can become more integrated into community life.

Participatory Action Research, the key methodology of the CR4AT project is also a key focus of the current NIDRR director and administration. A collaborative approach to research can incorporate consumer issues and the perspectives of the technology industry and rehabilitation profession. This style of research provides a means for more people with disabilities to accomplish two distinct goals. One, persons with disabilities will become actively engaged in the area of research – whether it is AT, medical rehabilitation or engineering. Two, the results will assist with long-range strategic planning for the federal agencies in regard to AT.

The six chapters of this book represent a starting place, not an end. The book is a way of sharing what the current knowledge is and suggesting how to move forward. The chapters, written by the CR4AT project staff with their collaborators, summarize the current state of issues for Assistive

Technology; this includes training, funding, availability, education, and the need for consumer participation in new technology. This work could serve as a catalyst for other initiatives leading to progress in the utilization of AT for people with disabilities. With the Center on Disabilities at the California State University at Northridge, the California Foundation for Independent Living Centers is well suited to be doing research by, for, and with people with disabilities. Consumers will be empowered by increasing their skills in research and advocacy. CFILC, with their enormous network of disability advocates and stakeholder groups, is positioned to not only be a conduit of information, but an educator in carrying out research related to AT use and design. Partnered with CSUN, with its long history of being at the forefront of promoting the awareness of available assistive technology, this project can further empower the disability community their efforts toward equality of opportunity.

A critical factor for the success of this project is consumers and researchers working with industry, engineers, employers and other stakeholders. This project is not just about "us" but also about how to make the system work better for everyone. It is pivotal that consumers get involved in the development of technologies at the "get-go". Simultaneously people with disabilities should be successful in obtaining employment and educating employers about the myths surrounding the costs and barriers in hiring people with disabilities. Barriers that exist at the attitudinal level can be overcome with training and education but technology has a way of making things possible.

It is up to the disability community to become more involved in editorial boards so that timely news pieces can highlight the usefulness of AT not only to people with disabilities, but to the general public as well. The more involved consumers are, the more they shape the direction of research that will identify their immediate needs rather than the needs perceived by the research community. Consumers provide applicability based on immediate needs that speed up the process of development. The research resulting from this process will help encourage and educate policymakers and other stakeholders to envision and design a society that is universally accessible for all.

INTRODUCTION
Asking Questions; Acting on Answers

Tanis Doe, Ph.D.

The very basic nature of research is in the asking of important questions. We determine which questions need to be asked through many different social and political processes, but nevertheless most research comes down to asking questions. When we ask a question we need to consider who might know the answer, how might the answer best be described and how will this new knowledge be useful. As we get better at asking the right questions we also develop different strategies for conducting research. The CFILC is using an approach called participatory action research to pursue important questions about assistive technology for people with disabilities. One of these questions is the title of this volume: *Is it working?* We hope to review how effective assistive technology is over the next four years.

Over time, we developed the ability to use tools to reach our goals. In the development of these tools we learned a great deal about science and technology. "Trial and error" and "invention" were strong contributors to the development of knowledge we now take for granted. Perhaps in another hundred years people with disabilities will begin to take for granted the equipment, technology and services that now enable their participation in social and economic life. But in the first years of the 21st century, we are still asking basic questions about who, what, where, when and how for assistive technology and people with disabilities.

The National Institute on Disability and Rehabilitation Research awarded a research grant to look at four main areas: employment, health, independent living and function. Within these four areas problems and solutions for accessibility and participation in the community are priorities. When we began the work of asking questions, we quickly identified two more crosscutting issues that needed additional research. Funding, especially under current health policy mechanisms, deserves special attention because of the role it plays in enabling or preventing access to assistive technology. No matter how progressive and innovative technology becomes, the cost of accessing it is still a significant issue. Throughout our initial pursuit of

answers we learned that funding problems, definitions and policy implementation across jurisdictions have a detrimental effect on people getting equipment and services.

In addition, we noted that there is a discrepancy in how people from cultural or linguistic minorities access technology. We are not certain why, but we know that more questions need to be asked and answered. We are also interested to discover more about sub-populations of people with disabilities, such as those in rural areas, people who have mental illness or cognitive disabilities and older adults.

In participatory action research the collaborating participants are also researchers and the researchers are part of an ongoing process of social change. This is quite different from the traditional objective, detachment of physical science and medical research, but people in their social systems are different than cells in a petri dish. The quest for understanding equipment needs and uses in their contexts supports the use of social science methodologies. Some of the answers we seek may be "common knowledge" in the disability community but undocumented in the research literature. Some of the answers might point to problems in universal design or the environment. But as the title suggests, we do not just ask the questions, we will act on the answers.

Action is taken upon identifying players and roles. This does not mean that the research becomes a service or a consumer-oriented program but that the information collected is used for the benefit of the population being studied. In the case of CFILC, the first year of research brought out significant need for dissemination of research. One of the results of this need was the collection of sample success stories found throughout this book. These success stories point to the effectiveness of technology and services in the lives of people with disabilities. Our preliminary research also identified a role for employers and consumers to increase understanding about technology in the work place. In our second year we will be distributing some information for employers and employees about technology. But CFILC cannot do everything, nor should it. Instead, we decided to ask consumer experts for their priorities before continuing to act.

Using the fax machine, email and the World Wide Web, the Community Research for AT project solicited input from 50 people on the priorities of

research questions. We took the lead from the Concerns Report Method, (Fawcett, Seekins, Whang, Muiu, & Balcazar, 1982) and created a new hierarchy of questions, rather than issues.

When CR4AT developed the list of potential research questions gleaned from the position papers "what we know now", we had far too many to actually accomplish. It was our intent to use the Community Concerns Research Questions method to develop a list of priorities that would be manageable. Although we had less participation than expected (only 52 people) we did get an overwhelming sense of what was important.

From the prioritizing we have identified several research questions that we will investigate as part of our second and third year's work. We have taken several of the research questions and put them into action statements that we will work on. CFILC will not do the work alone. CR4AT plans to take action with partners such as employers, health professionals, ILC's and people from diverse backgrounds. The design of the project was to be participatory, so we are sharing our results with you and asking for your involvement in both research and action.

Across the board- no matter what the subject matter, financial support for getting assistive technology was a high priority. Two of the questions that we will investigate are:
- *"What training and financial resources are needed to increase the use of technology by individuals from culturally diverse, rural and low-income communities?" and*
- *"How can Ticket to Work be used to acquire AT to make people with disabilities more employable?"*

These are both very specific and achievable research questions.

Three more research questions that were on the top list include:
- *What can be done to adapt standard technologies to ensure full access for people with disabilities?*
- *How can AT support people with cognitive and mental disabilities to more fully participate in their communities?*
- *How can ILC's and community- based rehabilitation services increase the use of AT among consumers with disabilities?*

These three priority questions will be investigated over the next year.

Action items are also going to be addressed this year. We turned some of the questions into items that could be achieved. The question, *"How can we successfully increase the participation of consumers with disabilities in the original design and development of equipment?"* becomes an action item to increase the participation of consumers in the design process. To this end we will work with rehabilitation engineering, industry and vendors and develop more communication about projects that could involve consumers at the design phase.

Since NIDRR funds a lot of the research, we will communicate regularly with NIDRR grantees and post information on our website about potential projects for consumers to participate in.

The next two questions have also been turned into action items regarding the dissemination of information and providing referrals. "*How can information, referrals, and resources be coordinated across numerous service providers of AT?"* and *"How can information, referrals, and resources be provided to people living in rural areas?"* CFILC has membership in the California Alliance of Information and Referral Services (CAIRS) and all the ILC members are actively providing Information and Referral. Our AT Network has a toll free Information and Referral phone line as well as a significant on-line database. The questions asked HOW to do something. We are going to take a step further and actually implement some processes to coordinate the information already available and to work to insure people living in rural areas are better served.

We need participation in this process so your help is welcome! Any ideas?? Employment is a huge issue for people with disabilities and AT has the potential to really make a difference. Research and action are both needed to deal with the issues regarding barriers and lack of resources. The Job Accommodation Network is a federally funded service that is free to callers and employers. One of the research questions that were written in (not on our original list) mentioned better utilization of this service. Another written in question was about employer awareness of the value of hiring disabled employees. "*How can we educate the major business world of AT's ability to help those with disabilities to be considered assets rather than 'invisible' liabilities?"* To address this, we have developed an employer survey (http://

atnet.org/CR4AT/surveys.html#1) and brochure that will be used as part of a marketing plan to increase employer awareness of AT and the capacity of people with disabilities.

In addition, our CCRQ responses gave us two other issues to act on in the priorities list. *"What marketing strategies could assist VR counselors to match people with AT?"* and *"How can we more fully involve consumers in the process of choosing their own AT and provide informed choices before purchase so they can obtain jobs in a variety of employer settings?"* Also, *"What do students with disabilities need in order to transfer school-purchased AT to the workplace?"* We plan to bring these to the attention of the Department of Rehabilitation and the school system in California and investigate possible solutions.

Much like the need for more awareness with employers, health professionals also are key players in the process of getting assistive technology. *"Do health care providers make AT available to their consumers?"* and "D*o people with disabilities who have access to specific technologies become more active, assertive, empowered managers of their own health care?"* Both these questions will be researched in the coming two years and we feel they will result in important findings for the community. In addition to these research questions we will also work on action items that emerged from questions.

"Does the availability of AT in hospitals, clinics, doctors offices, fitness centers and other health care settings lead to more successful health outcomes for consumers served by those facilities?" This is a research question that goes beyond the capacity of CFILC in terms of scope, but we can take action on this issue. We will try to encourage and support the use of AT in hospitals, clinics, and health care settings. Perhaps another project will be able to look at the impact on outcomes for consumers.

"How can we more fully involve consumers in the process of choosing their own AT and provide informed choices before purchase?" This is a key to independent living and the CFILC mandate. More information is more power. Having knowledge empowers people to make their own decisions. Not only will we work with employers and health care professionals but we will also partner with the AT Network and the ILC's to ensure more consumer information is circulated and made accessible.

Research is about asking questions. Technology is about getting things done. We want to ensure that this research project seeks out answers and acts on them for the benefit of people with disabilities. One of the tenets of participatory action research is to use consumer/experts as co-researchers. The participating Independent Living Centers of CFILC have sent their staff to ongoing training sessions to learn how to facilitate focus groups and work with qualitative data. In the coming years they will also learn survey questionnaire construction and implementation. The next step in the research plan is to develop a survey of Californians who use AT to collect broad demographic and use information. We will also be collecting data to answer questions emerging from the focus groups for the particular topics of employment, health, function and independent living. With this new data set, CFILC anticipates being able to inform the consumer and industry populations about AT needs and effectiveness.

This research-based knowledge will become the new standard for what we know. We already know there is far more out there to be researched than we have time for. We want to focus on the key issues that will have meaningful outcomes for people with disabilities. The best way to do this is to have people with disabilities leading the research and the action. CFILC is pleased to have the CR4AT project demonstrate the effectiveness and sustainability of participatory action research led by and for people with disabilities.

DIRECTORS' COMMENTS

Patricia Yeager, California Foundation for Independent Living Centers
& Harry "Bud" F. Rizer, Ph.D., Center on Disabilities –
California State University Northridge

People with disabilities in California, and throughout the United States, are consistently participating more in their communities and consequently expecting more. After the Americans with Disabilities Act of 1990 was implemented the standards for access rose dramatically. People who were previously isolated were riding busses, going to events, getting jobs and being active in civic life. The legislation could not change attitudes but it could regulate access and require accommodation. Assistive Technology has enabled many people with disabilities to achieve result that were until recently considered impossible. The federal government has a significant role to play in enhancing the lives of people with disabilities. The National Institute on Disability and Rehabilitation Research (NIDRR), an agency of the Office of Special Education and Research, has contributed greatly to research, development and action on issues for people with disabilities.

The California Foundation of Independent Living Centers (CFILC) and the Center on Disabilities at the California State University at Northridge (COD at CSUN) are uniquely qualified to serve in a leadership capacity in the area of research on assistive technology (AT). The wheels of action research were set in motion when NIDRR awarded a grant to CFILC and COD-CSUN. With Assistive Technology (AT) and systems change advocates in almost every independent living center, and university renown for its efforts to accommodate students with disabilities in the post-secondary educational environment and their annual technology conference, this was an innovative partnership like no other.

Before we even began there were visions of collaborations and action to improve the lives of people with disability through Assistive Technology. There was a great deal of enthusiasm about documenting the effectiveness and utility of AT throughout the community. As we started planning the research we realized that more than we expected, the research itself would be an empowering and effective tool for people with disabilities.

Despite the federal AT Act of 1998 and efforts by researchers, there seems to be a gap in the literature in terms of documenting and analyzing the issues around AT for people with disabilities. Some things we knew as common sense- expensive equipment was hard to get, doctors and medical professionals had to be willing to support device choices, industry and consumers were not well informed about each other, and there is stigma associated with using some technology. Common sense is good, but we needed to research existing information to determine exactly where we were before initiating new research.

During our first year of research we were fortunate to have many opportunities to speak with key players in the AT field. At conferences, meetings, and technology exhibits we developed a better understanding of the issues and challenges. Through a substantial review of the literature, the research staff developed four papers to cover the NIDRR priorities: function and access, Independent living, employment and health. While doing this research we identified the problem of funding as a cross cutting issue and decided to summarize existing issues for California as an additional paper. The research also pointed to a dearth of information about how minorities were using AT and what barriers they faced. A sixth paper was created drawing from the existing literature.

These papers became the chapters in this book. The decision to make these papers a book did not come lightly. Being in the first year of a five-year process we hesitated at producing such a document. However, our initial contact with consumers, industry and other researchers pointed to the fact that existing knowledge about AT was not adequately disseminated. Some people went as far as to tell us not to do more research, just act on what we already know.

Our research design uses a participatory action model. We are training disabled people and IL staff as researchers and engaging the community in prioritizing and analyzing the issues that they face. We must listen and listen carefully to what they tell us. They made it clear that action was needed immediately, not in year five. They also told us that employers needed more information and that funding was still a significant barrier to using AT. With this support, we proceeded to compile this book for dissemination.

CFILC is using an ecological approach to community research and technology. The ecological approach analyzes issues at individual and environmental levels as they impact all AT stakeholders, including the disabled. The four areas identified as priorities include employment outcomes, health and function issues, technology for access and function; and Independent living and Community Integration. Using a participatory research approach, CFILC plans to use an ecological model to develop cumulative research data about and around the use of and access to AT for people with disabilities. Participatory action research engages the people in the community to actively participate with the research from initial design to final presentation of results. The structure includes capacity building for research and training, and steps to ensure knowledge dissemination and utilization. Each step includes objectives at both the individual and system levels. Skills gained will result in professional development for those learning research skills and will allow for increased capability of data collection and dissemination of AT resources to effectuate an AT public policy impact.

AT at the individual level of use will be considered along with the environmental and design issues of access and AT. In addition, the interface between individual users and the environment at work, play and home will be central to our analysis. We want to show people with disabilities how important their participation is in this knowledge-generating project. They are the experts in their own lives and need to
be heard.

A RESNA-NIDRR collaboration found that 64 percent of persons with disabilities age 18 and over used some form of AT. This estimate is based on a prevalence rate of disability among adults in the United States of 16 percent. Put differently, 10 percent of adults in the United States or nearly 21 million people, not counting persons under age 18, used some type of assistive technology to help them with their daily tasks and activities.

Persons with disabilities and family or household members paid for AT out of pocket in about 40 percent of the cases; private health insurance, Medicare and Medicaid combined accounted for about an equal amount (38 percent) of AT related expenses. In 8 percent of the cases AT, mostly mobility devices, were obtained at no cost.

This research concluded that more awareness campaigns and outreach activities are needed to educate persons with disabilities and their families and caregivers, as well as health care service providers about where and how to obtain AT-related assistance. We hope this publication will fill part of the gap in consumer and industry knowledge about AT. It is the beginning of a longer concerted effort by CFILC to ensure people get the information needed to increase their participation in their communities.

COD-CSUN and CFILC are pleased to present our first project publication- *Is it working? A review of AT Successes and Barriers*- and welcome your reactions, feedback and suggestions. This is your project as much as it is ours.

SUCCESS STORY

Assistive Technology & Independent Living

Steven James Tingus

As a university student from 1981 through 1994, assistive technology was not available to him to use because it was still in development at that time. For example, voice recognition software, which is a critical piece of technology that he now uses daily was just coming to the market and the cost was prohibitive for him as a student. Steven did, however, use various types of devices that had been specifically adapted to aid him in his studies. He has always used a power wheelchair that enabled him to move from class to class. Low technology aids such as pencil grips, book holders and modified lab equipment for his science classes were also used. However, the majority of the assistive technology that Steven used were basic items adapted to fit his needs and allow him greater accessibility.

Since his graduation from graduate school, the most prominent piece of technology that has empowered him in his career is the advent of voice-recognition software such as Dragon Dictate Naturally Speaking. Steven states that his voice-recognition software allows persons with physical disabilities the opportunity to dictate their work on a computer, which in turns aids in creating viable products for work such as reports, and other projects.

As a person with a physical disability, Steven states that the development of transportation programs and wheeled mobility devices have allowed him to venture out more and participate in community activities, and be more politically active. Because there has been such a focus in recent years on creating better access through public transportation for people with disabilities, Steven has been able to travel wide and far to participate in the various activities he is involved in. In addition, he states that improvements in wheelchair design have allowed him to travel greater distances and do more things in comfort. Some of the activities that Steven has been involved in within the past couple of years include the campaign for Doug Ose for Congress in both 1998 and 2000. In addition, Steven was a key figure in the 2002 George W. Bush presidential campaign, acting as a disability policy advisor and fundraiser.

For people who may not be using assistive technology due to stigma or discomfort, Steven suggests a great plan of action to motivate people is to try it out! Steven suggests that if you have access to the World Wide Web, do some research or searches on disability and technology and look at what's being used by all people with disabilities. To look at what CFILC and other disability nonprofits are doing to advance independence of persons with disabilities through Assistive Technology. He also says that one should learn more about the funding mechanisms that would allow people to purchase AT in a cost-effective manner – use all of this information as a guide to where to go to be assessed, then go get the proper assessment.

So, first find out about the technology and the funding. Second, find out what organization can provide assessments to recommend the proper technology. And lastly, he says that everyone must recognize that we are all aging with a disability or aging into a disability so the need for AT will increase with age and everyone will need it at some point in their life. The thing is to decide what works for you.

For those who may feel a stigma associated with the onset of a disability and the use of AT, Steven suggests that one identify local peer support organizations that may have a specialty group or brown-bag group that deals with looking at aids for daily living, like AT. Then get into a group so that you can see what your peers are using to enhance their quality of life. See what works for others to see what may work for you – learn by example.

Steven James Tingus is a disability policy leader and advocate as well as a person with a physical disability due to a rare form of Muscular Dystrophy.

CHAPTER 1

The Effectiveness of Assistive Technology in Enabling Independent Living and Community Integration: What we know now

by Tanis Doe, Ph.D. and Amy Noakes, B.S.

Introduction

People with disabilities are participating in community life more than ever before and are taking control of their lives with the support of technology. The use of technology in the lives of persons with disabilities is bringing about a "paradigm shift" that is redefining the meaning of disability in our culture (Daniels, 1990). The old perception of people with disabilities in society, which derives from the medical sciences, is based upon the assumption that disability is a physical or mental deficiency that is not desirable. Under this individual deficit paradigm, people with disabilities are regarded as in need of special care or services that will cure them or else help them to adjust to their "affliction."

Daniels calls the new perspective the "technology/ecology" paradigm. Under this paradigm, disability is defined as a "lack of fit between a person's goals, his or her capabilities, and environmental resources."
In this paper we will example the technology that helps individuals with disabilities fit their environment and the environment fit them.

What are Independent Living and Community Integration?

The independent living movement has produced a model that emphasizes consumer direction and support. This model rests on the assumptions that people with disabilities have rights and that they should be provided with

suitable services to support their goals. Individuals with disabilities of all types have shifted from a dependence on agency service providers to an active use of community-based supports. In the support model, consumer choice, customization of needed services, and consumer empowerment are of increased importance compared to the traditional model in which service agencies emphasized professional competence, accountability, and quality control by service providers, and the safety of clients. Technology and medical services remain tied to the rehabilitation field but change is occurring rapidly.

Independent living recognizes that each person has the right to independence through maximum control over his or her life, based on an ability and opportunity to make choices in performing everyday activities. It does not, and should not, mean that people must perform functions without assistance. Some activities include: participating in community life; fulfilling social roles, such as marriage, parenthood, employment, and citizenship; sustaining self-determination; and minimizing physical or psychological dependence on others. Community integration incorporates ideas of both place and participation, so that a person is physically located in a community setting, and participates in community activities. This focus is necessary because of the traditional segregation of people with disabilities in distinct and often distant locations. As a movement, community integration had a primary goal of the deinstitutionalization of people with mental retardation or mental illness and has succeeded in moving many individuals from large institutional settings into the community.

Independent living has been integral to the development of the disability rights movement. This movement primarily has used a civil rights approach to demand equal access for people with disabilities, leading most notably to the passage of the Americans with Disabilities Act (ADA) in 1990.

While independent living emphasizes independence, whatever the setting, by its very nature it is a concept that also promotes participation, especially in community settings. At a philosophical level, independent living addresses the question of equity in the right to participate in society and share in the opportunities, risks, and rewards available to all citizens. It provides a belief system to a generation of people with disabilities. The new paradigm of

disability is an outgrowth of this philosophical concept of equity, bringing social and environmental elements to the meaning of disability. Disability has been defined as the expression of a physical, cognitive or emotional limitation in a social context, or the result of the interaction between a person's capacities and the demands of his or her environment (Brandt and Pope 1997).

The technology/ecology paradigm is an evolving framework that is characterized by a unit of analysis on the group level, interdisciplinary orientation and expanded range of disciplines including disability studies, business management and information systems.

Assistive Technology on two levels:
Universal Design and Tools for the Individual

Technological innovations benefit disabled people at the individual level and at the systems level. At the individual level, Assistive Technology enhances function; at the systems level, technology provides access that enhances community integration and equal opportunity. Most Assistive Technology for disabled individuals falls into the category of orphan technology because of limited markets; frequently this technology is developed, produced, and distributed by small businesses. This means the equipment does not have enough demand to produce high economic rewards for manufacturers. In order to increase the demand, more people must be willing to invest in technology for people with disabilities and one way for this to happen is at the systems level. Instead of increasing demand by individuals, we can increase the demand among the larger community. Often, technology on the systems level involves larger markets and larger businesses.

Access to technology can be increased by incorporating principles of universal design into the built environment, information technology and telecommunications, consumer products, and transportation (Parrino, 1992). If builders, designers and policy makers integrated important accessibility features into the way environments are constructed it would benefit many people and reduce the specific costs that are tied to the smaller market of people with disabilities.

Universal design principles can be applied to the built environment, information technology, and telecommunications, transportation, and consumer products. Telephones, for example should be usable by deaf and hard of hearing people, blind people, people with limited reach or mobility, people who need visual cues and the general public. Even crossing the street can be made more accessible by improving signage and curb cuts, providing audible light cues and establishing traffic patterns that are predictable. These technological systems are basic to community integration, education, employment, health, and economic development. The application of universal design principles during the research and development stage could incorporate the widest range of human performance into technological systems. Universal design applications may result in the avoidance of costly retrofitting of systems in use.

Ron Mace defined Universal Design as "designing all products and environments to be usable to the greatest extent possible by people of all ages and abilities" (Mace, Hardie and Plaice 1991:2).

While the potential benefits of technological innovations are often assumed, there also are potential problematic issues about accessibility, equity, and application of communications, information and transportation technology and how these issues affect independent living and community integration. In conducting this project questions will be asked about how people of color and underserved populations are accessing Assistive technology (World Institute on Disability, 1991).

What is Assistive Technology?

Assistive technology (AT) is defined as any item, piece of equipment, or product, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities. (P.L. 101-407, The Technology Related Assistance Act of 1988).

Perhaps most striking are the continuous developments in telecommunications and information technology. Accessible computers and Internet infrastructure as well as universal or specialized communication devices afford access to information and interactions among people with

disabilities, their families, advocates, service providers, employers, and others. Despite the potential for real time communication and information access promised by the internet access, there are significant inequalities in who has access to the technology. Research is needed to provide solutions that ensure new technologies increase participation rather than result in isolation for people with disabilities.

How does Technology Enable?

Technology can be empowering in many ways by allowing a person with a disability to direct their own activities and decisions. At the most basic level communication is enabled with telephones, telephone devices for the deaf (TTY) and communication devices. On the low technology end, pictures and words on paper or a communication board can support someone who does not use speech. On the higher technology end, computer generated speech can talk for a person who presses specific areas or keyboards in a comment. Blind people can read text by using optical scanning recognition and speech or Braille output (Kapperman, Heinze, Hahn, and Dalton, 1997). People attending school, going shopping or meeting with a doctor need to be able to communicate effectively and AT such as communication devices helps them communicate as needed in an effective manner.

Other technology used to control environmental surroundings include remote controlled doors and lights, intercoms and controls for music, television and computers set up on voice activation or push button systems. Some of these devices have now become popularized for mainstream consumption but they make the difference between independence and dependence for many people with disabilities. Putting Braille on the microwave and providing extensions on oven controls are other examples of readily achievable changes. High tech solutions for people who use computers include voice output and input devices, speech and breathing activated keyboards and mice and captioning on video images (Hall, 1997). Captioning on television is used by deaf people to read the text that is being spoken but it can also help people learning English as a new language and young children beginning to read (Harkins, 1996). People with mobility impairments or dexterity limits are able to operate equipment through electronic remotes rather than asking someone else to help. In another sense, these devices are also enabling people to become parents, employees and students.

When people with disabilities are parents there are a number of adaptive techniques they use to take care of infants and children. Through the Looking Glass has catalogued a number of the innovative technological devices for child and baby care. These include specially designed cribs, bathing equipment, carrying devices and alerting devices. People who are deaf or blind have developed many useful ways to keep track of young children using sound sensitive lights or bells that alert to movement.

Getting around in the community is especially important to a sense of belonging in the community. Without mobility people are isolated in their own homes, whether that is shared with others or not. Having an electronic mobility device or a suitable manual wheelchair also helps reduce the need for transportation. When long distances are involved, public transit, taxis and specialized vans with lifts make the community accessible for people with mobility limitations. There are some people who were restricted to their homes because of limited ability to walk or move around who can now be employed or attend school with their mobility aids. It also enhances safety because designs for wheelchairs and electric mobility devices are made to health specifications that take into account balance, weight and mobility (Adams and Beatty 1998).

Tactile markings on streets and buildings, chirping streetlights and Braille in elevators are examples of other technology that supports independent mobility for people with vision impairments. Even having an elevator or automatic door, which benefits everyone, can be seen as Assistive Technology if it would otherwise not have been installed. Mothers pushing baby strollers, older people, people carrying boxes or people who are just tired can all take advantage of an elevator or door that opens on its own. At shopping malls, office buildings, and service agencies, these doors, elevators and accessible designs promote the participation and independence of people with disabilities. Not only can people be active citizens but they can also work in these environments once they are made barrier free.

Many technologies address the environment rather than the individual capacity and thus spread the cost for installation and maintenance across the whole population instead of resting on people with disabilities. In another paper the CFILC describes the use of Assistive Technology for function especially related to sense and personal capabilities. Many devices that are

supportive are not "medical" in nature and are designed with more than people with disabilities in mind. Examples of these are electric can openers, lever style door handles, faucets for one-handed use and large print telephones (Enders, 1990).

While there is a wide range of generic devices that meet a universal need for access, there are many other pieces of technology that require customization and professional/consumer collaboration. It is very important that the fit of the device to the person (and the situation) is made appropriately. Without a proper fit the person may abandon the equipment and resort to alternative, perhaps less effective means (Batavia and Hammer, 1989; Phillips, 1992).

Financial barriers to AT

As it was stated earlier, some of the technology that is most suited to people with disabilities is considered "orphan" technology because there is such a small market for these highly specialized devices. Industries may not be interested in doing development on equipment that will only have a small rate of return. The non-speaking population is small and companies that serve them are small too (Seelman 2001). "While third party payers may fund devices for individuals, the devices must usually meet medical not social use criteria" and the funding for equipment is usually tied to a medical or professional recommendation or prescription (Seelman, 2001 p 665). The higher end devices almost always cost more and are more likely to be paid for by an individual or insurance company. The lower cost devices are often easier to fund through public mechanisms.

Technology that is medically necessary may be available to disabled people who have personal resources of health insurance (either private or public) that will pay for the equipment. The newer, more community-oriented technology is not always covered, even in countries with universal health care (Enders and Litvak, 2001 p. 718).

The Medicare definition (at the federal level) is that "durable medical equipment" can withstand repeated use, is primarily and customarily used to serve a medical purpose, generally is not useful to an individual in absence of illness or injury and is appropriate for use in home (42 CFR 414l202). The

mention of home-based equipment has often limited funders and prevented financing for employment or community integration related devices. Assistive technology is all equipment that enables people with disabilities anywhere.

> In other words, if the products selected required you to consider your disability issues first, then they are Assistive Technology even if they are widely available, mundane or mass marketed products. When your disability is defining or narrowing your product choices and options you are buying Assistive technology whether you are calling it that or whether it was designed to be AT (Enders, 1997 p.17)

Ultimately, decisions about investments in research and development are decisions that can support or deter independent living and community integration and learning and working in the community. For example national science and technology policies could incorporate the principle of universal design and could make research and development investments in universal design applications for transportation, the built environment, telecommunications and consumer products (Seelman, 2001 p. 664).

One of the problems is fragmentation because the process is market driven. Newell (1988) argues that Assistive Technology research priorities and characteristics are different from those of health research and that the medical model is seldom appropriate for researchers in this field. He believes that such researchers should focus on the needs and wants of users, and this is achieved by a user-centered design methodology (p. 673). CFILC considers this essential in conducting research and will include users of AT throughout the research project.

Funding is often limited to equipment deemed *medically necessary*, a term subject to interpretation by health insurers. From the disabled persons' perspective a wheelchair and software are AT much like van lift or splints. Support systems interact and overlap if the environment is designed to meet needs of people with disabilities. Assistive Technology provides consumers with control over tools when they do not have the power to alter the environment (Enders and Litvak, 2001 p. 716). Arbitrary distinctions are made in resource allocation especially in service systems based on a medical model.

It is possible that AT can reduce the severity of impairment and decrease disability by reducing the demand of an activity or increasing a person's capacity to perform the activity. The best fit for AT, support persons or animal has often been limited because of restricted information, funding and availability (Institute of Medicine 1991).

Medical and rehabilitation professionals, policy makers and the general public, often no not recognize how important integration and individualization of supports are. Barriers between professional differences in funding streams and compartmentalization of disability services are major stumbling blocks to achieving integration and responding to changes in circumstances of individual disabled people (Enders and Litvak, 2001 p. 712)

Barriers to support systems

The broad definition of technology implies the interaction of individuals, materials, and machines in a variety of instructional settings and employing a variety of strategies—each item of the mix being called upon to do what it does most effectively. According to the World Institute on Disability, in discussing the Assistive Technology and related services needs of persons with disabilities:

> A second important concept is that people with disabilities should be regarded as problem solvers. Unfortunately, the history of people with disabilities in the U.S. and elsewhere has been, in large part, one of paternalism. Entire professions of "experts" have emerged who have obtained degrees, and also taken control over basic life decisions away from their clients. However, recent trends have demonstrated that, given the proper tools, people with many different types of disabilities can devise creative approaches to eradicate barriers that had stumped the so-called experts. (World Institute on Disability, 1991)

Too many people are in nursing homes because they do not have the very modest support that would allow them to live in their own homes. This absence of support can be attributed to community deficiencies, such as lack of accessible housing and lack of sufficient funding for personal assistance services, Assistive technology and lack of adequate independent living skills, reluctance to take such huge risks, and lack of family support.

And, it must be acknowledged, lack of leadership and aggressive action on the part of many independent living centers and disability-focused organizations (Batavia and Hammer, 1989).

One study examined 341 nursing home residents with developmental disabilities to compare changes in functioning among individuals who moved into the community with those who stayed in the nursing home. This two-year study found that residents who moved into community settings experienced significant health benefits, while those who remained in nursing homes experienced deterioration or no significant changes. Decreases in anemia, obesity, overall health problems, number of days of hospitalization, and mobility limitations were observed among those who left the nursing home. Persons who remained in the nursing home experienced increased speech impairment, circulation disorders, and level of adaptive functioning (Heller, Factor, & Hahn, 1995).

According to the U.S. Department of Housing and Urban Development report to Congress, <u>Worst Case Needs for Housing Assistance in the United States in 1990 and 1991</u>, individuals with disabilities suffer acute housing problems and "face the most pressing unmet housing needs" of any group which qualifies for housing subsidies. According to the report, "worst case renters"—individuals who are very low-income renters with "priority housing problems," including those who are involuntarily displaced—pay more than half of their income for rent or live in severely substandard housing.

About 47% of individuals with disabilities who receive subsidies from the Department of Housing and Urban Development (HUD) fall into the "worst case" category, a much higher percentage than other low-income housing recipients, even though people with disabilities generally have preference for admission into federal rental assistance programs.

People with more significant disabilities face complex needs beyond initial location of affordable, accessible housing. While group homes allow more community integration than institutions, residents of some group homes still have little control over their lives and often remain isolated from the larger community (Rothman & Rothman, 1984).

The type of independent living program advocated by the disability rights movement is based upon a nonmedical empowerment model and differs

from medical model programs in several significant ways. First, the independent living model puts the consumer, rather than a medical professional, in charge of his or her own care. The involvement of a medical practitioner is minimized, and a "lay" person generally provides the daily personal assistance. This person is not affiliated with a certified home health agency, but is an independent provider, often someone already known to the consumer. Second, the consumer, rather than a home health or professional agency, generally hires, fires, and often pays the assistant. The consumer sets hours and terms of employment. Third, the consumer, rather than a professional agency trains the assistant to provide the help he or she needs. Several states, such as Massachusetts, Kansas, and Pennsylvania, have adopted consumer-directed PAS (Personal Assistant Services) programs, either committing state resources or using Medicaid waiver provisions. However, adoption of such programs is dependent upon the strength of the disability advocacy community seeking to advance the cause of independent living in each state (Alliance for Technology Access, 1999).

The consumer control model recently has been adapted to serve people with limited cognitive ability by allowing a surrogate, such as a friend or family member, to perform management functions, like hiring, training, and ongoing supervision of the assistant. In many such cases the use of Assistive technology provides enough support that the consumer can live independently. An essential element of this model is the ability of the consumer to choose a surrogate. Consumer and surrogate together decide which tasks each will perform (Scherer, 1996).

Much of the research to date has been based on a social sciences or rehabilitation paradigm and looked specifically at the individual from the medical-model perspective. More research is needed that looks at the environment and the person in context from an independent living perspective. This type of research is best done by and with people with disabilities.

Areas requiring more research

1. How can information technology be made more appropriate for people who use languages other than English?
2. What are the impacts of applications of telecommunications innovations

on independent living and community integration outcomes?

3. What can be done to adapt standard technologies to ensure full access for people with disabilities?

4. What are the barriers to participation in the community, including those resulting from inequitable distribution of technology?

5. Are there unique or additional barriers that people of color face in trying to access AT? How can we successfully increase the participation of consumers with disabilities in the original design and development of equipment?

6. How can technology reduce isolation among people with disabilities?

7. What uses and potential does portable phone and pager technology have for supporting independence of people with disabilities who may need prompting or cues?

8. What are the potential innovative applications of telecommunications and information technologies to expand opportunities for informed choice, independence, communication, and participation?

9. How can assistive technology support people with cognitive and mental disabilities to more fully participate in their communities?

SUCCESS STORY

Assistive Technology & Employment

Bob Segalman, Ph.D.

Dr. Bob Segalman is a Research Analyst with the California Department of Rehabilitation and the National Founder of Speech-to-Speech. He currently serves on the National Federal Communications Commission (FCC) Consumer/Disability Advisory Committee. He holds both a MS and Ph.D. in Social Welfare/Sociology from Florida State University and the University of Wisconsin, respectively. Dr. Segalman is one of three Californians with profound cerebral palsy to hold an earned Ph.D.

For the last 29 years he has worked for the State of California in various capacities, including positions as a Social Worker with the Department of Developmental Services and as Disability Consultant for multiple departments. During the 1970s, he also worked as an Assistant Clinical Professor of Pediatrics with Loma Linda University. But he would not be able to perform these jobs without Assistive Technology (AT).

When he first began his career with the State of California in 1972, Dr. Segalman used a walker to get around and a typewriter for his written correspondence. One of his biggest difficulties was using the telephone. Due to his voice, which is at a whisper because his vocal cords do not work, it was difficult for people to understand him over the telephone. Today all that has changed.

Due to the many advances in AT, Dr. Segalman is able to use multiple types of technology to perform his job as a Research Analyst with the California Department of Rehabilitation. Word prediction software has replaced his typewriter at his desk. With this program, the computer "predicts" his next word in a statement based on previously typed words. This technology helps to reduce the number of keys he types. A power wheelchair has replaced the walker, and a modified vehicle with a wheelchair lift and hand controls instead of foot pedals allows him to easily drive himself to wherever he wants to go. He is thus able to travel independently.

But the biggest innovation for Dr. Segalman has been his own. Dr. Segalman is the National Founder of an AT service called Speech-to-Speech (STS). STS is a type of relay service that provides communication assistants (CAs) for people with difficulty being understood over the telephone. STS helped to eliminate the big telephone problem. Now, when he needs to talk on the telephone, Dr. Segalman calls toll-free to reach a communication assistant who places his calls and repeats his words for him so he can be better understood by the person on the other end of the phone line. This service has made it much easier for him to perform his job.

Unfortunately, there are many people with disabilities who still do not use AT. Some people are unaware of what types of technology and services are available to them. According to Dr. Segalman, currently only 500 people in the United States use STS, but over 2 million people could benefit from this service if they knew it was available. Having more money for outreach and education would greatly benefit the public. This is also true for STS. By doing outreach to the public, we could increase the use of AT by helping people to understand what it is and educating people to feel better about using it.

CHAPTER 2

The Effectiveness of Assistive Technology in Improving Employment Outcomes: What we know now

By Amy Noakes, B.S. and Tanis Doe, Ph.D.

Introduction

Before CFILC began engaging in new research, we wanted to see what the existing literature said. What are the barriers to employment that assistive technology can remove? Does assistive technology improve employment outcomes? Who pays for the technology? What about assistive technology that is used for those who work at home? Other papers in this series will address assistive technologies that aim to support access to health services, independent living, or function. This paper will focus more narrowly on the effectiveness of assistive technology in enabling disabled people to achieve employment.

Assisting individual with significant disabilities in moving from dependency on public benefits or family support, or from episodic poor paying jobs into stable jobs that will allow them to become self-supporting is a complex challenge (NIDRR, 2001). Leaving the public subsidized health care system is often difficult for people with disabilities. In the Welch and Flynn Investigative Study on the Impact of Using assistive technology on the Job, (1997) "one study participant said it cost him $100 more per month to work at his job…than it would for him not to work." Medical coverage for illness, and payments for attendant care and transportation are all part of the benefits people could receive on public support such as Social Security Disability Insurance. These benefits can range from $18,000 to $30,000 a year. For many, producing an income that would make up for the loss of benefits could take a number of years (Buchen, Pulich, and Wenkman, 1998, p. 34).

One of the state based program for people with disabilities is the 250% California Working Disabled Program. This Program is a Medi-Cal buy-in program that allows workers with disabilities to earn up to 250% of the federal poverty level and still buy Medi-Cal insurance coverage with a monthly premium payment (Jeserich, 2002). According to the Federal Poverty Level Guidelines, 250% of the federal poverty line for a single individual in 2001 was $21,475 and for a family size of two it was $29,025. 250% of these amounts are $53, 687 and $73,125 respectively.

In the last decade the social and political emphasis has shifted away from dependency on state support to being able to work. Now, people with disabilities are supported to go to work in part by providing continuation of some benefits. Benefits for people with disabilities include coverage for prescription medication and health services that would be too costly if paid for independently. Health care concerns are connected to employment by the threat of losing health insurance, which influences the decision for a person with a disability to become gainfully employed. Federal initiatives to improve the labor force participation of people with disabilities is recognizing the diversity of disability and cultural subgroups among the larger population (NIDRR, 2001).

Despite political will to encourage labor market participation, public assistance programs and employment programs for people with disabilities often seem at odds with each other. The public health care system's definition of disability assumes a relationship between severe impairment and permanent disability and the inability to work. The public health care system is poorly informed regarding what eligibility requirements are required to maintain assistance with employment. The state and local government social service administrators are under-trained. Consumers and employers need to know what types of equipment are helpful in the workplace for persons, with a wide variety of disabilities, doing a range of jobs. The literature review begins with policy barriers and continues on to look at vocational and individual level barriers and successes in the use of AT.

Legislation and Policy issues:

The *Assistive Technology Act of 1998* (Tech Act) identifies policies that facilitate payment for assistive technology. The Tech Act also identifies policies that impede payment for assistive technology and barriers in federal AT policy. Assistive technology (AT) is defined as any item, piece of equipment, or product, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities (P.L.101-407, The Technology Related Assistance Act of 1988).

Title I of the 1990 *American with Disabilities Act* (ADA) prohibits discrimination in employment. Specifically, a person with a disability is qualified for employment if he/she can perform the essential duties of the position. If the essential function cannot be performed, the employer must consider if the function can be performed with a reasonable accommodation. Lastly, the employer must provide a reasonable accommodation unless it would be an undue hardship on the organization. Essentially, Title I of the ADA protects people with disabilities from being discriminated against in the workplace. It promotes the concept that impairments are not and should not determine a person's potential for participation in the workforce (ADA, 2002).

The *Rehabilitation Act of 1973* is another federal policy that has an effect on employment outcomes for people with disabilities who utilize Assistive Technology. The Rehabilitation Act stipulates that Vocational Rehabilitation counselors are available as a resource to provide rehabilitation-engineering services for needed worksite accommodations (See Section 504, Rehab Act, 1973).

These acts and the way they are implemented are responsible for the technology, devices and equipment that enable people with disabilities to participate in society. However, barriers remain preventing people with disabilities from achieving their full potential due to technology and funding problems.

Definitions:

Reasonable accommodations: Employers are required to make changes and adjustments so that persons with disabilities can enjoy equal opportunities in all aspects of employment. These changes and adjustments are called "reasonable accommodations." These may include providing new devices or changing current equipment so that persons with disabilities can perform a job (Protection & Advocacy, 2000, p. 6-1).

Self-employment: Working at home in a business or as a consultant without directly reporting to an employer.

Telecommuting: To work at home by the use of an electronic or phone based connection with a central office. Telecommuting can also be defined as the use of alternative work locations for employees who are normally based in the office (Merriam Webster Dictionary, 2001).

Vocational Rehabilitation: The federal Rehabilitation Act provides for vocational (VR) and independent living services to people with disabilities. In California, the agency responsible for providing VR services is the Department of Rehabilitation (DOR). VR services include any service, training, counseling or equipment that a person with a disability needs to achieve your employment goals. Vocational rehabilitation includes assessment, planning, development and provision of vocational rehabilitation services for individuals with disabilities so that those individuals may prepare for and engage in gainful employment consistent with their strengths priorities, concerns, abilities, capabilities, interests, and informed choice. (Title 1 of the *Rehabilitation Act of 1973* as amended (Act) 29 USC 701-744)

Communication related issues at work:

Effective interpersonal communication is one of the most important aspects of employment. Without communication on the job, employees would not be able to interact with management, coworkers, and clients. For persons who have speech or communication disabilities, Assistive Technology can bridge the communication gap. Some examples of communication AT on the job would consist of written notes or instant messaging for a hard of hearing or

deaf employee. E-mail can be used for someone with a stutter. Augmentative and alternative communication devices can be used for persons with cerebral palsy who have difficult-to-understand speech (Job Accommodation Network, 2001). "Success in the work environment is not only being able to carry out the work tasks, but also requires competence in social skills, which requires having adequate means of communication" (de Jong, Rodger, Fitzgibbon, 2000, p.78, section 1.2). Technology can improve the access to communication, however it does not replace the importance of positive attitudes, respect, and understanding.

Telecommunications:

Telecommunications is communicating at a distance, for example using a telephone. Numerous adaptations exist that enables a person with disabilities to communicate effectively with others outside of the workplace. Technology can range from something as simple as a head pointer used to dial the phone to something very high-tech such as voice output. For example, "a blind receptionist was provided a light probe, which allowed her to determine which lines on the switchboard were ringing, on hold, or in use. A light probe gives an audible signal when held over an illuminated source, and cost ranges from $50 - $100.00" (Protection & Advocacy, 2000, p. 6-15).

In the work place a device does not have to be specially designed for disabled people to be useful. Some technology that is common to many workers is effective at improving how an employee with a disability works. The most common telephone accommodations include amplifiers, telephone headsets, cordless headsets, speakerphones, extendable phone holders, and programmable and automatic dialing features. Other telephone accommodations that can be implemented are lights and sensor probes for the hearing impaired, large print labels or locator dots for the visually impaired. For persons with speech disabilities, voice output on the phone is a solution. In addition, many hard of hearing and deaf employees utilize instant captioning for conference calls and email text. For those with visual impairments, audio messaging, talking caller ID, and tape recorders are all examples of assistive technology that assist in telecommunications in the work place (Job Accommodation Network, 2001).

Computer Access and Employment:

As modern technology advances, personal computers are used in almost every office in America. For many persons with disabilities, computers have opened the doors of employment that were previously closed to them before the prevalence of computer technology. Computers give people better access to looking for work, preparing for a job search and interviews, better performance on the job and better opportunities for lifelong learning. According to the Chartbook on Work and Disability in the United States (1998), "eighteen percent of those who are working and eleven percent of those who are not currently working reported that they need a personal or laptop computer to be able to work effectively" (Stoddard, Jans, Ripple, & Kraus, 1998, p.39).

Numerous computer access adaptations are available for workers with disabilities to conduct their work effectively. Accommodations for the computer range from very simple to very complex solutions. Examples of low-tech solutions can be as simple as changing the font size or contrasting colors using the display feature built in to the computer. Adding large-print labels to the keyboard or computer can also aid someone who has problems seeing the small letters on the keyboard. Other input devices that assist persons with mobility impairments include adapted keyboards, keyboard guards, trackballs, touch pads. For example, a keyboard guard keeps a person's fingers from slipping to nearby letters on the keyboard. It allows the user to concentrate on one key as needed. Other devices such as anti-glare or anti-radiation computer screen guards are used for people who may be chemically sensitive.

High tech solutions include voice input/output software, screen magnification software, larger sized monitors, special computer glass to reduce glare, software programs for self-editing, word prediction, or grammar spell-checkers. For blind, visually impaired and some learning disabled people, the use of screen readers to verbally announce what is on the screen has enabled significant opportunities in employment. In addition, non-AT computer accommodations include taking frequent breaks to rest eyes when fatigue may be a factor or garnering additional training when needed.

Low Tech Support for Manual Skills on the Job:

Manual skills or physical access skills are can be as important as computer skills when working. To aid the person with a disability, items such as arm supports, writing & grip aids, page-turners, book holders, note takers, ergonomic workstations, to-do lists, calendars, electronic organizers are all available. Simple modifications such as a step stool or small ladder can be used for shorter people. To aid in writing, things such as pen/pencil grippers, orthopedic writing devices, handle build-ups, and weighted pens can assist. In addition to these readily available, low-cost devices, many people invent their own systems to provide alternatives to traditional work done by hand.

> A high school guidance counselor with attention deficit disorder was having difficulty concentrating due to the school noise. The school replaced the bell on his telephone with an electric light device, which lit up when the phone rang. They also soundproofed his office and provided a floor fan for white noise. The accommodations cost under $600 (President's Committee on Employment of People with Disabilities, 2000, p.7).

Getting to work and moving around:

While telecommuting is becoming a viable option for some people, it does not replace the need to get to and from the traditional workplace. Getting to the worksite, entering and using the site can be very difficult if adaptations or universal design features are not incorporated.

Mobility in the workplace is a critical issue for those with disabilities. Access to offices, the restrooms, coworkers' desks, files, and storage are all daily activities of employment. Assistive technology can eliminate many of the barriers encountered in the work place for both the employees as well as persons visiting the workplace. For example, power doors, accessible parking, accessible rest rooms, accessible routes of travel to other work areas, lever door handles, ramps, and handrails are all items that can be universally designed to ensure that anyone entering the work place can move around easily and safely.

Restrooms are a problematic area for those with disabilities. For example, a person in a wheelchair must be able to enter the bathroom. If the door is too

heavy, or there is not enough room in the bathroom stall, that person is not able to use the rest room at all. Using the restroom is an important function within everyday employment.

Universal Design:

Universal design is an industrial design method intended for the general public in which devices and buildings are made to be universally accessible. Items like the grocery store electric doors that open and close by using a sensor, are considered universal design. Elevator buttons, bank machines, telephones and information kiosks all have the potential to be universally designed. Elevators that include instructions in Braille, visual floor displays and audio call outs of the floor and the direction the elevator is traveling is an incorporation of universal design, (California Foundation for Independent Living Centers, 2001). "Another example would be volume amplification on telephones which was originally designed for the hard of hearing, but can be very helpful to everyone in noisy environments such as an airport" (Alliance for Technology Access, 1999. p. 11).

Every work place has the potential to be universally designed to accommodate any person of any ability. According to the American with Disabilities Act Accessibility Guidelines (ADAAG) many of the universal design features are incorporated into the structural guidelines for any building. These include accessible parking spaces being designated for people with disabilities as well as elevators in buildings of more than one level or even lowered counters for community work spaces, such as in a mail room or reception area.

Employers can also incorporate universal design features into many aspects of a physical workplace. Ergonomic workstations benefit not only the person with a disability, but all employees. The same goes for telephone headsets. Computing devices are used in almost every facet of business in today's world. By including ergonomically correct computers/workstations and using the accessibility features included on many operating systems injuries and illness can be prevented. Power doors are also considered universal design. Suppose an employee is loaded down with too many items in their hands, power doors allow the opening and closing of the door with ease. Power doors in the restroom also allow visitors to easily access the lavatory without relying on assistance from others.

Manufacturers of assistive technology are looking to universal design methods to reach a broader market. This includes making assistive technology more aesthetically pleasing, and less stigmatizing for consumers to use. This philosophy aids in enhancing employment by creating technology that fits in with the work environment. It can be something as simple as creating a volume control on a device so that it is not distracting to other employees when in use.

Orientation on the job:

As people with disabilities enter the workforce, more attention will need to be given to orienting them to the employment settings. Orientation on the job refers to not only physical access but includes activities such as filling out paperwork, emergency evacuation, reading the employee handbook, insurance, and many activities that one does not normally think of as work. For many with visual disabilities, this orientation process can be a time of confusion as well as frustration. Employers have a responsibility to provide alternative methods of orientation for new employees. Ways to accommodate those with visual impairments in the orientation process are not too complicated. Some solutions include creating alternative print methods such as Braille, large print, or even having the materials read aloud on audiotape. Braille is the least cost-effective method, whereas audiotape can be done for free in many areas. For example, the Lions' Folsom Project for the Visually Impaired utilizes the Folsom prisoners to do audio recordings for organizations at little or no cost (Lion's Folsom Project for the Visually Impaired, 2002).

Health and Safety:

Safety on the job is critical for the entire workplace. Someone with a mobility disability may not be physically able to use the stairs during an evacuation. Additionally, those with hearing impairments are not able to hear audio smoke alarms. If someone with a cognitive impairment is employed in the work place, they need to understand instructions for evacuation during an emergency. Assistive technology enables a person with a disability to be notified during an emergency in the workplace. Some of the technology available includes vibrating pagers and flashing lights for those with hearing

impairments. Audio alarms exist for persons with visual disabilities. Providing equipment such as a stair lift is another safety feature that can be installed in an office for persons with mobility impairments.

There is also an evacuation chair now available in California. Evacuation chairs are specially designed chairs to help get mobility-disabled people down the stairs in the event of an emergency. These were used during the September 11, 2001 bombings on the World Trade Center in New York.

> "Not fully realizing what exactly had happened, it was obvious they had to get out. On the 68th floor, Benfante and Cerqueira encountered a woman in a wheelchair. The woman, a rheumatoid arthritis sufferer, had also been in the building during the WTC bombing in 1993. The two men helped the woman out of her wheelchair and into the special evacuation chair. It was an hour-long descent to safety. Once outside, Benfante and Cerqueira placed the woman in an emergency van" (Eustice, April 2002, par. 4).

Another precaution that employers can take is creating a safe plan for evacuation, which includes pictures, symbols, or diagrams for safe exiting. Alerting the fire department of the probable location of the person with a disability is another safety feature that can be implemented when an office employs someone with a disability.

Alternative Employment:

Telecommuting is becoming commonplace in the United States. Over 30% of the general workforce participates in some form of telecommuting. Computers have opened up the doors to allow many people to work at home. According to a survey conducted with employers, some of the reasons telecommuting programs began include the retention of valuable employees which lowers recruitment and training costs and responding to employee's needs which keep morale high. In addition, employers were able to fill positions for positions that had previously been difficult to fill (Jarret, 1996).

A national study indicated that 12% of Vocational Rehabilitation clients needed some type of home-based employment in order to participate in the

workforce (Rumrill, Fraser, & Anderson, 2000, p.3). "Telecommuting provides companies with the opportunity to successfully integrate workers with disabilities for whom the traditional workplace presents obstacles," (Virginia Commonwealth University, April 2002).

It is estimated that at least "40% of small businesses are operated by a person with a disability" (U. Miyares, personal communication, October 21, 2002). This includes both home-based and storefront businesses. Of those in business who have a severe or significant medical condition, the population is between 3% and 8% of all businesses owned by a person with a disability. The 1990 census revealed that 12.2 percent of people with disabilities are self-employed.

According to the 1993 US Census, 27% of the American population lives in a rural environment (U.S. Census, 1997.) Rural areas have a limited range of services, less than reliable transportation system, and less specialized services. In addition, rural residents use a higher percentage of their incomes to pay for services in a rural area. The Research and Training Center on Rural Rehabilitation Services identified 44% of people with disabilities who live in rural areas are participants in employment assistance programs such as Medicaid and Medicare.

Self-employment and microenterprise are becoming viable options. Self-employment and microenterprise usually require less than $35,000 for start-up (Mathis, 2002). Companies such as the Abilities Fund, that assist in connecting people with disabilities to monies for microenterprise and new programs such as the Individual Development Accounts, are making microenterprise a more feasible option for those with disabilities (Leydorf, 2002).

Barriers faced by employees:

• Stereotypes and Attitudinal Barriers:
"Maintaining employment for people with disabilities is dependent upon their ability to advocate for themselves" (de Jong, et al. 2001, p. 78, section 1.2). People with disabilities face many attitudinal barriers when looking for gainful employment. Although most of these attitudes are found in the public, employers and career professionals, people with disabilities also have barriers relating to attitudes. A lack of motivation, lack of competence in

social skills, and a fear of disclosing a disability and repercussions of disclosure are just a few individual issues that can impact joining the workforce.

In a study conducted with Human Resource departments, supervisors, and co-workers, several perceptions emerged regarding the use of assistive technology and employing persons with disabilities (Butterworth, Pitt-Catsouphes, 1997). The parties surveyed felt that there was a lack of knowledge regarding accommodations and compliance requirements under the law. They stated that the legal protections for persons with disabilities seemed so complicated and vague that a lawsuit was imminent (Butterworth, Pitts-Catsouphes, 1997). Due to this lack of knowledge, many employers carefully scrutinize a person with a disability prior to hiring because they felt it would be difficult to terminate them once hired if employment didn't work out. This behavior also led to the "norm to be kind" which means employers are not providing negative feedback or poor evaluations when warranted to their employees with disability (Butterworth, Pitt-Catsouphes, 1997). This in turn raises an equity issue for persons with disabilities.

Cultural perceptions of attitudes towards one's disability can also heavily influence outcomes of vocational rehabilitation services and employment (Velasco, 1996). A study conducted with Hmong female refugees with psychiatric disabilities revealed that in Laotian culture it was "considered disgraceful to allow a family member with a disability to work or participate in household chores…the village takes care of them," (Velasco, 1996, par. 16). The conclusion of the study discovered that "cultural barriers proved to be a significant barrier to participating in supported employment," (Velasco, 1996, par. 25).

Other attitudinal barriers may include lack of support by family and friends, family responsibilities. Employment programs can create a problem if they provide incomes below the poverty lines but with enough income that disqualifies them from much needed medical benefits provided by the state. Systemic barriers include a lack of reliable transportation, inadequate training for competitive employment, and the heavy burden of proof for those with hidden disabilities.

- Information and Marketing Barriers:

Information and self-marketing are key components for anyone looking to enter the workforce. For a person with a disability, finding the information regarding assistive technologies is usually garnered from a medical professional. This can include what is needed, how to obtain it, maintain it, and use it (Abouhassan, 2001). In a Californian statewide needs assessment regarding assistive technology, other cited sources of information included other people with disabilities and friends who have experienced a similar need as a way of getting information… as well as trial and error (Abouhassan, 2001). Most physicians are unfamiliar with the range of AT available. A much smaller number of individuals told that they obtained information regarding assistive technology as a result of self-advocacy or service they learned about through vendors or any type of outreach fairs. Other informational barriers include the general lack of knowledge of AT and the limited training on AT for individual users (Abouhassan, 2001). Problems range from not knowing how to get the assessment to procuring the device and who is responsible for payment of these services.

The consumers must advocate for themselves over and over again in order to obtain the needed technology to participate actively in employment. This includes knowing one's rights under the law, and knowing and understanding the requirements and eligibility rules of each funding source. It also includes knowing specifically what type of technology is needed and the ways the device can improve functioning.

Organizations that match people with disabilities with employment do exist, such as Vocational Rehabilitation, Independent Living Centers and other agencies. Vocational Rehabilitation is a central information source regarding employment, which has the potential to play a vital role in matching employees with employers of gainful employment. However, "rehabilitation is not simply about placement and training or about jobs and employment, rather rehabilitation is about introducing new resources and a new way of thinking," (Menz, 1997, p.10).

Employers rely on the employee to specify what technology is needed, however there is sometimes a reluctance to advocate in the workplace for fear of being alienated of compromising employment opportunities (de Jonge, et al. 2000). Many placement organizations have aided in facilitating

employment for persons with disabilities, however some individuals felt that the "advocacy efforts may have caused a negative reaction from the person making the hiring decision," (Butterworth & Pitts-Catsouphes, 1997, p. 7). Even more so, easy-to-locate community resources for information regarding assistive technology are rare.

Lastly, employer non-compliance with the ADA poses yet another barrier for people with disabilities having positive employment outcomes. Accessible application processes and interviews, workstations, restrooms, and alternative formats are all tenets of the ADA. However, many companies are not in compliance, therefore making it difficult for persons with disabilities to engage in employment. For example, if a blind person comes into an office to fill out the application, is the application available in Braille or other alternative format. What if a wheelchair-user comes in for an interview and cannot get into the interview room because of inaccessibility? If someone requests a reasonable accommodation once hired, and the employer requires copious amounts of paperwork and documentation, is this not also considered discrimination? "Both private sector and federal organizations report a difficulty responding to requests to make information accessible for people with visual or learning impairments, and making information accessible for hearing impairments" (Bruyere, 2000). "Many employers act in a 'politically correct' manner, yet propagate a discrete discrimination process…post ADA discrimination has become more subtle," (Cooper, 1995, p.84).

• Policy and Financial Barriers:
The statewide needs assessment data reports that the most frequently used sources of funding include Medi-Cal/ Medicaid and the state Department of Rehabilitation (Abouhassan, 2001). However, funding technology through these venues is a convoluted process. Separate eligibility requirements, types of AT funded and cost of AT is different under almost every funding source in California. For example, Medi-cal and Medicare will only fund a device if it is considered "medically necessary". Many of the funding agencies for assistive technology have different definitions of AT; one agency may call it durable medical equipment while another agency calls it assistive technology. Public benefit programs focus on medical necessity and/or only equipment that can be used in the home. The lack of focus on other areas traps consumers who need the technology for other uses, such as employment.

In addition, if the consumer ends up purchasing the device out of pocket financial reimbursement for AT is unlikely. AT paid for by insurance shows more frequent abandonment due to the determinations of needs and authorizations being based on third party payer criteria versus consumer choice. "Third party payment also significantly distorts the market and are unresponsive to the consumer needs," (as cited by UCP, 1993; O'Day, 1993; in DeJong and Brannon, 1996, p. 10). Participants in the needs assessment expressed a want for limitation on bureaucracy, denials and delays to obtain the necessary devices (Abouhassan, 2001).

These are real-life every day situations that persons with disabilities face. The lack of education and attitude regarding disability proves detrimental to many persons with a disability. While there is reprieve from instances such as this by filing a lawsuit, the lack of understanding regarding the law leaves many feeling helpless and without resources.

• Health care concerns:
Additionally, once a person has gained employment, most often, the employer-paid health plans do not offer AT or do not provide health care due to a preexisting condition. Or even worse, they offer the care, but the premium is so high as to be unaffordable for the person with a disability. Another paper in these series will address health care concerns, but lack of medical benefits can be a substantial barrier preventing persons with disabilities from participating in mainstream occupational opportunities. The Workforce Incentive Improvement Act we hope will reduce some of these disincentives to employment (WIIA, 2000).

• Technological Issues:
Sometimes assistive technology removes barriers for persons with disabilities so that they can engage in employment. However, the technology can also prove to be a barrier in the workplace. For example, incompatibility with other devices, updates in office hardware software as well as an improper assessment on the appropriateness of equipment can all be detrimental once in place on the job. The integration of AT in the work environment can create rigid structures and locations of the technology, thereby locking an AT user into a specific worksite. This leads to the inability to be mobile around the office, such as working with another person at their desk (de Jong, et al 2000).

Another barrier that technology can pose in the workplace includes having outdated, unreliable technology or technology that is not compatible when the office systems get updated. Compaq and Microsoft recently published their findings on their effort to reduce the amount of time needed for AT manufacturers to produce products that were compatible with new or upgraded operating systems. Microsoft recently launched their new version of Windows XP. Before launching they worked with eight vendors who produce AT devices such as screen readers and speech output for the visually impaired to see if the time needed to create compatible products with new operating systems could be reduced from the standard eighteen to twenty-four month period. The results were positive (Moulton, 2002). However, Compaq's and Microsoft's "Time to Market Effort" is just one attempt on the part of major manufacturers to create compatible products.

Getting technology to use in the workforce presents problems as well. AT professionals can act as gatekeepers to determine access thereby creating tensions between the traditional service model of delivery and the newer more favored consumer-oriented models (DeJong & Brannon, 1996, p.3). Additionally, some consumers do not always obtain an appropriate assessment or the appropriate equipment to perform the needed job functions. The guarantee of after sales service, training, and a backup system are often overlooked when obtaining technology.

Lastly, the user needs to obtain some sort of satisfaction from using the device. If the user is not satisfied, this will impact work. "When choosing a device, it is necessary to determine the perceptions and expectations of the user because if these are not met, device satisfaction will be low," (Welch & Flynn, 1997, p. 2). Users of AT also need some type of positive reinforcement to let them know that the AT is bringing about positive change in the work environment for the person with a disability.

- Barriers to Employment Alternatives:
Many of the vocational programs that are successful in urban areas are not successful in the rural areas due to economic inequity. People with disabilities who live in a rural area are in need of employment alternatives. Some alternatives to employment that exist include self-employment, microenterprise, and telecommuting.

Self-employment and microenterprise are viable employment options. According to a study based on the percentage of Vocational Rehabilitation closures due to self-employment, conducted by the University of Montana, self-employment is only used by 2.6% of the national disability population (Arnold, Bernier, Seekins, 1997, p.166). Vocational Rehabilitation counselors do not often promote self-employment as a vocational goal. Some policies contain incorrect data regarding the high rate of failure regarding self-employment. Eleven states have no written policies, procedures or guidelines for self-employment as a vocational goal. In some states, self-employment is only an option for those considered severely disabled (Arnold, et al., 1997, p.167).

There are also unrealistic expectations of traditional resources towards people with disabilities. The lack of a support system in employment alternatives is an overwhelming barrier for many people with disabilities. Inexperience with business start-up, management, and a tentative commitment are many of the barriers one may face when creating a plan for self-employment. Low readiness on the part of the person with a disability and unrealistic expectations are also causes of failure in self-employment or microenterprise (Walls, Dowler, Denetta, Cordingly, Orslene, & Greer, 2001).

Telecommuting, though it may seem an excellent alternative for those who cannot get into the workplace, also poses several barriers. The employer must first determine whether the work or assignment can be completed off-site. In addition, the employer must answer whether or not the supervisor is capable of managing by monitoring the results rather than direct supervision. Most importantly, does the employee have the proper equipment to conduct business at the home? (Jarrett, 1996)

Supports to Employees:

Although there are numerous barriers a person with a disability faces when employed, supports for employment are sometimes successful. The reasonable accommodation process in employment, personal supports, information and marketing geared towards employment of people with disabilities as well as maintaining insurance are all supports available for employees with disabilities.

Numerous organizations have specific intent to support people with

disabilities in the workplace. The Job Accommodation Network is a free consulting service "that provides information regarding job accommodations, the rights under the law for people with disabilities and information regarding the employability of persons with disabilities," (Job Accommodation Network, 2002). The Governor's Committees on Employment of People with Disabilities provide general information regarding how each state administers its non-discrimination programs. Another resource for information on employment support is the Disability and Business Technical Assistance Centers (DBTAC's). The DBTAC's provide information, training, and technical assistance to people with disabilities and employers. Yet another support system available for persons with disabilities is a mentoring program. This can range from a support group at a local Independent Living Center to the Toastmaster's chapters located throughout the nation.

Barriers/problems for employers:

Often, a person with a disability has difficulty accessing the services and resources needed for accommodations from an employer. This lack of participation on the part of the employer can be the result of attitudinal barriers. There exists a misperception regarding disability and job accommodations. Due to either ignorance, fear of setting precedents, or lack of top management supports, many accommodations in the workplace are difficult to get. Unfamiliarity with discrimination legislation makes employers hesitant to discuss the true needs of the person with a disability (de Jonge, et al. 2000). Additionally, many employers require copious amounts of documentation because they may not understand the disability or there just may exist a lack of motivation to educate them regarding disability, assistive technology, and reasonable accommodations. Due to the lack of understanding on the part of the employer, many misperceptions exist regarding cost of accommodations, cost of training as well as placing more emphasis on the disability rather than less (Butterworth, Pitt-Catsouphes, 1997).

• Employer policy regarding accommodations:
Due to the misperceptions regarding disability and accommodations, employer policies can also become barriers for those looking for employment. In many organizations, accommodations are not offered on a formal basis; therefore those with a disability are on their own to find needed

accommodations. Others may have limited support from the organization to resolve their accommodation issues as well. Since people with disabilities may have more reason to take time off work for doctor's appointments or sick leave, they may be penalized because changes in these policies are not adjusted. A lack of equity by ensuring equal pay and benefits and by using the same guidelines creates inconsistency between policy and practice (Butterworth, Pitt-Catsouphes, 1997). "Not only must policy change, but workplace culture must change as well. Organizations need to unlearn some of their values and learn new ones" (Barrett, 2000, p.6).

• Vocational Rehabilitation/other job placement services:
Vocational Rehabilitation services are designed to get Californians with disabilities prepared for employment and can include training, education, transportation and job placement (Department of Rehabilitation, 2002). Unfortunately, many of the jobs people are trained for as clients of Department of Rehabilitation do not provide a qualified employee pool for employers. Currently, many employers feel that services provided by DOR, such as the types of work plans created, and the lack of continued training designed for advancement in the workplace do not exist (Gilbride, Stensrud, Ehlers, Evans, & Peterson, 2000). This creates a lack of qualified employees with disabilities. For example, someone trained to work on an assembly line more than likely will not be considered for a position with competitive wages and the ability to move up the corporate ladder. Many times, employers are not aware that they are even served by Department of Rehabilitation (Gilbride, et al. 2000). Rehabilitation counselors often times fail to adequately consider and integrate necessary AT into the work place for a client of DOR, which in turn results in a failure of competitive employment.

Vocational Rehabilitation could enact several changes on the policy level in order to create a viable system of qualified employees that are able to compete in corporate America. By collaborating with other programs, such as the Small Business Administration and conducting research on the short and long-term outcomes of self-employment, the job pool could be increased for employers wanting to hire people with disabilities. An ongoing discussion with graduates of Vocational Rehabilitation and the counselors also ensures that the person will receive necessary training and education to ensure that they do not stagnate in one position. Vocational Rehabilitation agencies can also consider managing their relationships with employers in the communities so that more employers know that Vocational Rehabilitation is

a resource for employment. By expanding the services Vocational Rehabilitation provides, such as assistive technology recommendations, evaluations and some assistance with funding assistive technology, employers may view Vocational Rehabilitation as a viable and effective resource as well (Gilbride, et al. 2000).

The Department of Rehabilitation in California must also be timelier with providing evaluations and assistance for assistive technology to its clients. People who are blind have lost jobs because the Department of Rehabilitation did not buy the needed equipment that they agreed to purchase in a timely manner. In one case, the person was fired after six months of employment because DOR failed to purchase the needed equipment (Herb Levine, personal communication, 2002).

Supports for Employers:

• Employer Education/Training:
Addressing employer concerns so that workplaces are favorable environments for people with disabilities is of paramount importance. Several modes of focus can be adopted. Organizations such as World Institute on Disability offers ADA training programs for corporations and businesses who want to learn more on the issues surrounding accommodations for persons with disabilities. In addition, they also provide disability awareness training (World Institute on Disability, 2002). By educating themselves, employers begin to understand the benefits of hiring persons with disabilities to create diversity in the workplace. Such education lessens the fear of the ADA as well.

• Peer support from other businesses:
Peer support is a core belief of the Independent Living philosophy. By incorporating it into use with businesses, the consumer-oriented service model is perpetuated. Peer support enables organizations to hear success stories from other businesses, understand that not all accommodations cost money, as well as the understanding that not all disabilities are physical (Harrison, 1998). The California Business Leadership Network is an "active alliance of California companies who are collaborating to improve employment for people with disabilities" (www.cabln.org, 2002). They have created a website that discusses everything from recruiting to emergency preparedness as well as guides to understanding different disabilities. Other

information supports include WorkSupport.com, the Job Accommodation Network and the National Organization on Disability.

- Funding:

While most businesses are responsible for the cost incurred to make reasonable accommodations for employees with disabilities, some funding does exist that lessens the cost. It usually is not much money, but does provide incentive for businesses to comply. The three tax credits include the Disabled Access Credit, Architectural & Transportational Barrier Removal Deduction, and the Work Opportunity Tax Credit.

The Disabled Access Credit is a tax incentive program designed to encourage small businesses to comply with the ADA. It is equal to 50% of "eligible small expenditures" that exceed $250 but not more than $10,250. A maximum credit can be taken by small businesses of $5000 a year (Fedworld). The Disabled Access Credit is intended for use by any small business whose gross receipts do not exceed $1,000,000 for the preceding tax year or who employ less than thirty employees. The eligible employee for whom the accommodation is being made must be a full-time employee that works at least thirty hours a week and has been employed for at least twenty calendar weeks during the tax year. The Disabled Access Credit can remove architectural barriers such as installing power doors or ramps. It also includes removing communication barriers such as installing a text-telephone for a deaf employee. Providing interpreters, qualified readers for the blind, audio format, and other methods to deliver materials to the visually impaired are all considered as eligible for credit under this deduction.

The Architectural and Transportation Barrier Removal Deduction is a $15,000 tax deduction used for removal of architectural and transportation barriers. Businesses may deduct up to the $15,000 for making their facility or a public transportation system more accessible to people with disabilities. It can be used for any part of a building, structure, equipment, road, sidewalk, parking lot or similar sort of property (Fedworld). However, this deduction is not valid for new construction, since new construction is covered under Title III of the ADA. It is also not used for complete renovation of a building but only partial renovation.

The last federal tax credit found is the Work Opportunity Tax Credit. Currently this tax credit is being voted on again. However, when it was in

effect, it applied for people who began work on or after July 1999 until January 2002. It includes a credit for persons hired from eight identified target groups, including Vocational Rehabilitation clients and recipients of Social Security Insurance. The employer received up to forty percent of the first $6,000 or up to $2400 in wages paid during the first twelve months for each new hire out of these programs (Fedworld).

Conclusion

The Community Research for assistive technology has identified major gaps in the employment of persons with disabilities. These include a lack of awareness on the benefits of employment for those with disabilities. A lack of universally designed technology that creates lower cost items for those on limited incomes. The laws and policies that provide assistive technology for the disabled worker need to be more comprehensive, consumer-oriented and better coordinated to create an accessible system of procurement. The definitions of many Income Assistance programs such as Medicare and Medi-Cal currently encourage the production of inappropriate AT and create market distortions as well.

Research questions that could be asked for this project include:

1. How can assistive technology increase the effectiveness of community-based employment service programs?
2. What is the result of AT and labor market changes on employment of people with disabilities, including alternative employment arrangements such as small business entrepreneurship, self-employment, telecommuting, part-time work, and contractual work?
3. What marketing strategies could assist VR counselors to match people with disabilities with appropriate AT to obtain jobs in a variety of employer settings?
4. What cost-effective strategies can be used to assess assistive technology adaptations of the workplace environment for workers with disabilities?
5. What funding strategies or alternatives can be developed?
6. What do students with disabilities need in order to transfer school-purchased AT to the workplace?
7. How can ILC and Community Based Rehabilitation services increase the

use of AT among consumers with disabilities?

8. How can AT be marketed better to improve consumer knowledge of its availability?

9. What training and support services are needed to ensure consumers continue to use AT to the best potential in the workplace?

10.   Statistics and hard data regarding small businesses for people with disabilities.

11.   How can the barriers in technology for voice mail and menu driven phone systems be overcome to meet the needs of persons with cognitive disabilities, deaf person, blind persons and people with slower manual dexterity?

12.   How can Ticket to Work be used to acquire assistive technology to make people with disabilities more employable?

13.   What, if any, role does AT have in changing the attitudes of employers and device industry professionals toward people with disabilities as workers?

14.   What else do we need to know?   What are the priorities in this area?

Research on the above questions should be carried out rigorously, and with significant input from, and direction by people with disabilities. NIDRR supports the use of participatory action research and use of the new paradigm of disability that integrates the individual and the environment to produce 'disability'.

SUCCESS STORY

Ethnic Minorities and Assistive Technology

Nicaise Dogbo

Nicaise Dogbo self-identifies as Black, and is an immigrant from the Ivory Coast (West Africa) who has lived in the United States for 15 years. He is blind and uses many different devices for communication and access. He uses scanners, a refreshable Braille display, synthesized speech output and a Braillelyte notetaker. He benefits from having the equipment both at home and at work. He said the AT "makes me very independent and helps level the field."

Nicaise first experienced life as an ethnic minority and discrimination due to his blindness when he first came to the US. In the Ivory Coast, once you can show you are productive, disability or not, you earn the respect of others. Here in the United States he has faced more discrimination. In addition, he was the only blind person in electrical engineering at his university. It was difficult at times without the appropriate support because professors had little or no experience working with students with disabilities and the technical subject of engineering.

"It was very challenging because of all the different battles I had to fight. There were people willing to work with me and once I demonstrated I was capable of doing the work, people started to understand."

The reaction of university staff to his disability and AT does not seem to be different among people in different ethnic groups. He knows that it is possible the use of AT makes his blindness more obvious, but this has not been a reason to stop using it. Nicaise feels there is nothing to be ashamed of in using equipment or having a disability.

"You shouldn't feel singled out. It's just another way of being. For some of us its visible and others it is not. Technology is not just a luxury thing for us, it's for access. Start using technology because it will help you be what you want to be and help you be at the same level as everyone else."

Nicaise knows its expensive but there are ways to get funding. He suggested that you might need to do some research to find appropriate resources. He was able to get some financial support through the Department of Rehabilitation, and feels this is a good place to start.

Nicaise is the Director of Employment/Technology Services at the Rose Resnick Lighthouse for the Blind and Visually Impaired in San Francisco. He has been blind since the age of 14 due to unusual glaucoma according to Western Medicine and witchcraft according to his native culture.

CHAPTER 3

Ethnic Minorities and Assistive Technology:
What we know now

By Myisha Reed, B.A. and Tanis Doe, Ph.D.

Introduction

In a review of the current literature on topics affecting individuals with disabilities, there is little, if any, information regarding ethnic minority groups and AT. This paper will introduce and explore some of the barriers faced by and differences among ethnic minority groups. Using existing information, we will provide examples of some important differences between the majority and minority disability groups in order to illustrate gaps and the need for further examination into this area. We will explore the known barriers for these groups as well.

What is AT?

According to the Technology Related Assistance Act of 1988, assistive technology is defined as "any item, piece of equipment, or product, whether acquired commercially, off the shelf, modified or customized that is used to increase, maintain or improve the functional capabilities of individuals with disabilities." AT can be simple or very complex, may be used in many contexts and can address a multitude of disabilities. Assistive Technology has helped people with disabilities in many ways. Individually, AT enhances function; systematically, it enhances community integration and equal opportunity in areas such as employment (Doe & Noakes, 2002).

Communication, for example, is an activity used in all aspects of life: home, work, and play. AT can provide a method to communicate with others. At the most basic level, communication is addressed with such technology as telephone amplifiers, telephonic devices for the deaf (TDDs and TTYs),

Braille writers for the blind and many other devices. For instance, to support a person who does not use speech, simple augmentative and alternative communication AT can include catalogues of pictures and words on paper or an electronic communication board. A more complex device addressing communication needs is computer-generated speech, which can talk for a person. The person presses specific areas on a screen or uses a keyboard on the device to speak. The blind can read text by using optical scanning recognition and speech or Braille output (Kapperman, Heinze, Hahn, and Dalton, 1997).

AT can also help to improve access to public places to allow persons with disabilities to become active in their communities. Wheelchairs, canes, walkers, and prosthetic limbs which address mobility-related disabilities, give people access to areas outside of their homes (Doe & Noakes, 2002). Cochlear implants might give a deaf access to a public meeting in the community (Doe & Hershey, 2002). This paper will show why the unique needs of minorities must be considered when exploring AT.

Who are the minorities and why?

Immigrants and descendants of immigrants from every corner of the globe, as well as Native Americans occupy the United States. Each culture, and to some extent each subculture within our own society, develops beliefs, practices and organizations to respond to the needs of its members as it concerns health, healing, and disability. All cultures also develop a technology, and a set of beliefs, practices and attitudes about that technology. Immigrating peoples and members of marginalized subcultures confront the United States' massive health and social network infused with a Western concept of health/healing and technology holding competing beliefs and practices, which are, nonetheless, equally well-organized and coherent. They must somehow fold themselves into the existing social systems, which categorize them much differently than they categorize themselves.

Consider the range of beliefs held by those people among us we term "Asian." The designation contains hundreds of cultures and thousands of subcultures. It is clear that all "minority" categories are woefully inadequate in a descriptive sense, and from the point of view of outsiders to our culture, almost arbitrary. Yet they exist, and each of us, immigrant or not, must

check a box on our census form. Government agencies and social organizations count the check marks, modify policies and programs, develop reports and publish documents. A social science literature has evolved that ceases to question categories but accepts them as "fact." New research and literature rephrases itself to fit these "facts" so that investigators are at least speaking about the same people in the same way. It is for this reason that, for the purpose of this paper, the following ethnic groups will be discussed: Native Americans and Alaskan Natives, Blacks or African Americans, Latinos or Hispanic Americans, and Asian Americans and Pacific Islanders. While recognizing these groups are composed of diverse sub-populations, the authors have chosen to use these designations because they correspond to the major racial and ethnic groups referred to by the United States Census Bureau as well as by much of the literature in the social sciences. It is only for the purposes of comparison with other works in the field, that these specific groups have been chosen for this study and the designations are not intended to stereotype any particular group or culture.

The 2000 Census reflects the following demographic makeup of the United States population:
- 75.1% White
- 12.5% Hispanic or Latino (of any racial background)[1]
- 12.3% Black or African American
- 3.6% Asian American
- 0.9% American Indian and Alaskan Native and
- 0.1% Native Hawaiian and Pacific Islander (US Census, 2000, Table DP-1).

It has been shown that ethnic minority groups have higher rates of disability than Whites (Fujiura, Yamaki & Czechowicz, 1998). This has been attributed to many factors, including: dangerous working and living environments, poverty, restricted access to adequate health care, and violence (McCrimon, 1994, as cited by Galvin, 1996, p. 56). Members of ethnic populations are more likely to work in physically demanding, high-risk and low-paying jobs, such as farming or factory work. Language barriers, limited education and low literacy rates are often contributing factors to this trend (Smart & Smart, 1997; Miller, 2002; Santana & Santana, 2001). Ethnic minorities are also more likely to be injured by firearms. In a study of spinal cord injuries between 1980 and 1993 conducted by the Regional Spinal

Cord Injury Case System of Southern California, 94.2% of the cases have been from ethnic minority groups (Waters, Adkins, Sie & Cressy, 1998).

According to Bradsher (1996) the overall rate of disability in the United States is as follows:
- 21.9% for Native Americans,
- 20.0% for Black/African Americans,
- 19.7% for Whites/European Americans,
- 15.3% for Latino/Hispanics and
- 9.9% for Asian/Pacific Islanders (p. 1).

The data shows that although minority groups make up a small proportion of the United States population, they constitute a significant proportion of the population of people with disabilities in the US.

Exacerbating the problem is the fact that people with disabilities of ethnic background do not receive services equal to their white counterparts (Kemp & Parette, 2000; Bau, 1999). Some populations, such as African Americans, may be skeptical of the health and social systems because of past discrimination. For example, the Tuskegee Syphilis Study (also known as the Tuskegee Experiment) conducted from 1932 to 1972, is a well-known case of systematic discrimination against African Americans. During this period the United States Public Health Service intentionally withheld syphilis treatment to over 300 poor Black sharecroppers. This research has become a powerful symbol for systematic racism, exploitation and government abuse of vulnerable people in the name of research (Tuskegee Syphilis Study Legacy Committee, 1996).

Cultural practices may also contribute to a lower incidence of obtaining AT. For instance, in the South Asian and East Indian cultures, spending patterns concerning family health differ significantly from the patterns in the United States. Pinto and Sahu (2001) report that many families prefer to spend their income on their remaining "healthy" children, especially the male ones. More money may be spent on the non-disabled children because these children are expected to be able to care for their parents in the future. A disabled child, on the other hand, is not expected to be able to work or provide for the family.

Families in minority cultures may also hold different expectations for a disabled family member. In many cultures the family, rather than the state, is expected to take care of a disabled family member. The disabled person is not expected to work and it is seen as disrespectful or selfish to decline this family assistance (Miller, 2002; Pinto & Sahu, 2001; Kim-Rupnow, 2001). A family member is always on hand to assist their family member.

In addition, families who have just arrived in the United States may not perceive that a disabled person has a need for AT. For many of these families, the stress and responsibilities that come with moving into a new environment may be of higher priority than obtaining technology for a family member with a disability (Bau, 1999). Getting an adult son to a vocational rehabilitation (VR) appointment for services may be impossible for a mother working twelve-hour shifts at a low-end job. Perhaps the family is busy trying to navigate health and social service organizations in order to have the basic necessities, so that getting VR services is considered a luxury. It is currently unknown how people in such situations are accessing AT, if they are accessing it at all.

Examples of differences between minority groups and the majority

Social systems, such as Vocational Rehabilitation, are established to provide assistance and support to all people with disabilities but are steeped in White middle class values and a Western ideology that often clashes with people of different backgrounds. Independence, empowerment and self-advocacy are terms and concepts that may be completely foreign. Western ideology is often described with terms such as individualism, freedom (defined as being free from another's control) and a strong work ethic (Bellah, Madsen, Sullivan, Swidler & Tipton, 1985 as cited by O'Conner, 1993; Golnick & Chinn, 1990 as cited by O'Conner, 1993). Work ethic, for example, is reflected in the organization of the social services for Americans with disabilities. As previously mentioned, in many cultures, a person with a disability is not expected to work, yet this is the focus of an entire department, Vocational Rehabilitation. A person is being rehabilitated so they may obtain a job, be independent and provide for themselves. The goals set by VR counselors may be in direct contrast to the client's cultural practices, which may include being supported by the family.

For many people from minority cultures, the idea of empowering a person with a disability to live on their own, away from their family is unthinkable. In the Latino culture, someone with a disability is expected to have their family and the surrounding community-care for them. Although functionality may be pursued so the person may contribute to the family, someone will always be at home to provide both care and protection. A certain amount of dependency is expected (Santana & Santana, 2001; Lopez-De Fede & Haeussler-Fior, 2002). South Asian culture tends to have similar practices. Women are usually responsible for the care of the family member. The idea of empowering the individual is generally seen as selfish unless this person is the head of the household. If the main wage earner becomes disabled, AT and disability-services may be pursued in order to maintain the household. However, the family would much rather provide for their own loved one than have them endure a low status job (Pinto & Sahu, 2001).

Other examples of beliefs held by some non-Western cultures include:
- *Having a "fatalistic" attitude.* The person with the disability may have a "if it were meant to be, it would be" attitude. By leaving things to fate, direct action is unnecessary. Kim-Rupnow (2001) reports fatalism among some Asian cultures.
- *Isolation of a person with a disability.* Some cultures may not believe that persons with physical disabilities need physical exercise, recreational activity or a social life (Lopez-De Fede & Haeussler-Fiore, 2002). If these are not perceived as needs, AT is not necessary to accomplish them.
- *Consumers may be unfamiliar with the concepts of rehabilitation and adaptation.* For example, a minority client may arrive at an initial appointment expecting a cure from the rehabilitation counselor and may leave very disappointed when it is not provided (Bau, 1999).
- *Attitudes towards professionals and service personnel.* Difference cultures may interact with professionals differently. African Americans, as previously mentioned, may distrust professionals; Latinos, on the other hand, may give great deference and high levels of respect to professionals; and Asian Americans may also be reluctant to seek service from professionals (Barrio, 2000).
- *Gender disparities.* In East Indian cultures, for example, females may receive less medical care than their male counterparts (Pinot & Sahu,

2001). If the female has a disability, she may never have had access to an assessment or any other means of obtaining AT.

As a final note, it should be remembered that the actions taken by the family members of minority people with disabilities are often taken because the family believes what they are doing is the "right" and "moral" thing to do within their cultural belief system and, of course, out of the love and protection they feel for their disabled relative. Sometimes the minority community is unsupportive of AT because they do not know how to respond to people with disabilities. Information about disabilities has not been made available to the people of these communities, so they do not know what actions to take. To ensure the family is not judged or ridiculed, people with disabilities are often kept in the home, sometimes away from the view of their community members (Pinto & Sahu, 2001; Batres, 2001).

What the literature says
Views on Disabilities
The lens a culture uses to view disability plays an important role in the actions taken in order to live with the disability. If disability is considered just an unfortunate occurrence of life, a disabled person may simply adapt and move on with life. But if disability is seen-as something negative, perhaps shameful, it may not be easy to accept or accommodate someone with a disability. The meaning of disability within the culture thus helps to determine the response to the disability (O'Connor, 1993; Kim-Rupnow, 2001).

Physical disabilities and mental disabilities may not be equivalent in some cultures. Frequently, physical disabilities are more readily accepted and seen as more "normal" than mental ones, perhaps because physical disabilities are more visible (Santana & Santana, 2001). In Chinese culture, for example, mental disabilities may be viewed as a result of weak character. The blame for the disorder is placed on the person with the mental disability (Liu, 2001).

Many cultures view disability through a spiritual lens. Although supernatural forces, such as witches, are sometimes the cause, disability may be a punishment for wrongs done by the disabled person, a relative or an ancestor. This is a common attribution in many faiths, including Christianity,

Buddhism, Hinduism, and Confucianism. Consequently, there may be shame, guilt, depression, and blame in response to the disability. Some people may even attempt to hide their condition from others to avoid the stigma (Pinto & Sahu, 2001; Miller, 2002; Lopez-De Fede & Haeussler-Fior, 2002; Liu, 2001; de Torres, 2002; Napier-Tibere, 2002). It is not surprising then, that assistive technology is often not used in these communities.

Use of AT
For some communities, low AT use is due to the lack of information. A study in 1997 found that after controlling for age, income and education, Black elderly used fewer AT devices, especially for vision and other sensory disabilities, than their White counterparts. The reason proposed by the authors was that the Black elderly may have less information regarding how to acquire and properly use AT and may have less access to professional offices and services (Tomita, et al, 1997). Information about AT is may not be reaching the areas where ethnic minorities live.

Others may be aware of AT devices that address their disability, but decline to use them. African American family members have reported they would rather not use devices in a public setting because they draw unwanted attention to the family (Smith-Lewis, 1992; as cited in Kemp & Parette, 2000, p. 386). Both African American and Hispanic American family members of children with severe disabilities often choose not to use augmentative and alternative communication (AAC) devices because they see them as unnatural and stigmatizing (Kemp & Parette, 2000). The response may be another attempt to hide the disability from others to protect both the family and person with the disability.

Barriers
Other barriers have been found to impede access to and use of AT by ethnic minorities with disabilities. The following barriers were cited by Galvin (1997) as those faced by many minority consumers with disabilities:

<u>Lack of Referral to or identification by the VR system</u>
Information regarding disability-related services is not adequately reaching minority communities. Background on independent living (IL), VR and AT services may need further interpretation before potential consumers understand all that is available to them (Sanderson, Schacht, & Clay, 1996

as cited by Sanderson & Yazzie-King, 2001, p. 73; Galvin, 1997). In a comparison of consumers' six most preferred formats for receiving disability research outcomes, it was found that disability researchers and stakeholders may be under-utilizing pictures, audiotapes and videotapes (NCDDR, 2002). Without the proper information being disseminated to them in a suitable format, there is a danger that individuals are not-identified by or referred to the VR system.

Some individuals are unwilling to request assistance from the VR and other social service systems. This may be due to cultural reasons. Seeking assistance from a source outside the family may be seen as revealing family secrets. Because disability may be associated with shame and guilt, discussing and revealing it to someone outside of the family is often taboo. Minority clients may not seek assistance because they may not identify themselves as "disabled" and therefore do not require AT (Alliance for Technology Access, 2000; Galvin, 1997; Kemp & Parette, 2000).

Attitudes of service delivery personnel and the general public
The attitudes held by the services delivery personnel can also be a contributing barrier. A study performed by Smart & Smart (1993) revealed that "rehabilitation practitioners tend to view acculturation as a predictor of clients' cooperation and success" (as cited in Wong-Hernandez & Wong, 2002, "Willingness to Cooperate section). If clients retained their native languages and cultural practices, they were viewed as high risk for being uncooperative and not working to reach rehabilitation goals.

Inequitable treatment by the rehabilitation system has already been well documented in the research literature. Rehabilitation cases of minorities are more likely to be closed without the clients being properly rehabilitated. They are also less likely to have counselors who set similar goals for them as for their white counterparts, so that many are not able to reach their full potential (Wong-Hernandez & Wong, 2002). As previously mentioned, racial and cultural bias can have harmful effects on the disabled consumer.

Difficulties in Service Provision
Disability tier systems have also contributed to a lack of access. If a disability is labeled as a "secondary disability," some service providers may not take the need for AT seriously. Service providers may feel that a secondary condition does not require as much attention as other disabilities.

The exclusion of AIDS patients from needed services, for example, can be the result of a service provider labeling the condition a "secondary disability (Galvin, 1997). According to National Institute of Allergy and Infectious Diseases or NIAID, (1997) minorities comprised 54% of AIDS cases in the United States with most of these consisting of African and Hispanic Americans. This can further limit access to available services for the consumer.

Racial, Ethnic and Cultural Issues
The cultural background of a consumer can alter the path the service provider must take to provide AT. It is important to remember that a person's cultural views and heritage are taken by the individual as facts and largely determine that person's identity. For those who continue to live out their cultures in the United States, especially those who have recently immigrated, adopting foreign concepts may be associated with a fear of losing themselves and their identity in the greater Western culture (Lopez-De Fede & Haeussler-Fiore, 2002). People may resist new practices in the attempt to have something to hold onto in an unfamiliar and often hostile environment.

Communication barriers
For the non-English speaking consumers, navigating the system can be very difficult. Although there may be a handful of bilingual service providers available, especially Spanish-speaking, there are not enough to meet the demand. There are also many languages and cultures left unaccounted for. The reliance on younger, more acculturated members of the family is an inadequate method to communicate between a consumer and a service provider. There are terms and concepts that may not directly translate between both languages, and a bi-cultural person familiar with disability and disability culture may be necessary to navigate these cultural differences.

There can also be a problem with the AT devices themselves. Augmentative and alternative communication (AAC) devices are an example. Some AAC devices contain pictures that the user presses when they want to communicate with others. A recent study examining the effect of culture and ethnicity on both word and picture types of communication found these meanings to be culturally determined among African Americans, Chinese-Americans, European-Americans and Mexican Americans. This suggests

that people may perceive all symbols differently, including pictures (Huer, 2000). The implication-of this is that AAC and other devices may need to be altered or redesigned for various cultures. There is a possibility that current AT may not adequately fit the needs of consumers with different cultural backgrounds.

Lack of resources to address needs of particular geographic populations
AT designed for use in urban areas requires sufficient energy as well as human resources that may be beyond the capacity of consumer's environment. Resources that many people take for granted, such as telephone access and electrical outlets, are not always available to poorer or rural dwelling individuals. Internet access, for example, can be impeded by the lack of electricity and telephone systems and the expense of access to long distance telephone service (Sanderson & Yazzie-King, 2001). The lack of basic resources in non-urban settings makes many varieties of AT, such as power wheelchairs, computers and Internet access, unavailable because the devices cannot be powered or recharged.

The tools used by the service personnel must also be adequate to meet the needs of the populations they are serving. In the case of AT assessments, the tools must be culturally valid, or misinterpretation and error are likely to occur (Santana & Santana, 2001). Cultural incompetence and ignorance can yield disastrous results. Equipped with the wrong information or the wrong tools, a service provider's best intentions can result in inaccurate assessments and inappropriate interventions (Bau, 1999).

Twenty seven percent (approximately 67 million) of Americans live in rural areas of the United States. There is a higher rate of disability among Americans in these areas than in urban settings (Galvin, 1997). Unfortunately, this population is often seen as "out-of-reach." Services may be provided twice a month for example, or on some similar interval-type basis. Getting an assessment from professionals, such as physical therapists, speech therapists, occupational therapists and psychologists, is often impossible (Tomita, et al, 1997; Sanderson & Yazzie-King, 2001).

If a consumer happens to get a needed AT device, there may be future problems, especially in regards to service on the device. Support and/or training services may be insufficient or unavailable in rural areas. There is often no one to check the fit of the device and to make sure that the

consumer is using the device properly. If the device happens to break, new problems emerge. If the consumer has a telephone and manages to contact some sort of customer care or repair service, vendors and service personnel may not be willing to travel to their remote location to fix the device. Consumers often must purchase an extended warranty from vendors to help ensure a service person will make needed repairs (Sanderson & Yazzie-King, 2001). This may be an expense the consumer cannot afford.

Lack of transportation
Three minority groups compose the American rural population of approximately 27%: Native Americans, Southern Rural African Americans and Mexican Americans (Galvin, 1997). Many who are poor may not have access to reliable transportation to receive disability and AT services. For 41% of rural American residents there is no public transportation at all; another 25% have access to extremely inadequate public transportation. When there is public transportation, it is usually by vans or small buses that operated on strict routes and schedules and within specific boundaries. Many of these vehicles are not wheelchair accessible (Spas & Seekins, 1998). Retailers of AT devices are not local to these communities, so browsing the nearest dealer for a piece of AT equipment is not an option far away from a more urban or suburban setting. The consumer may need to make difficult arrangements to travel miles into a more urban setting to obtain needed services or information.

Depressed economy/job market
Poverty has been identified as a contributor to disability. Native Americans, African Americans and Latinos often experience poverty and high unemployment. Native Americans and African Americans also tend to experience poor health. Lacking adequate health insurance, consumers may have to rely on what they can get. On Native American reservations, Indian Health Services and Community Health Representatives usually provide "low tech" AT, which may include manual wheelchairs, canes and portable commodes. Unfortunately, these may not be the proper fit for the consumer. Unless the consumer has private insurance, personalized measurements are not taken and personalized fittings are not done (Sanderson & Yazzie-King, 2001). The consumer is simply given a piece of "generic" AT that may or may not adequately suit their needs.

With poverty, unemployment and lack of health insurance as contributing factors, minority consumers may have few options available to them to pay for AT. Families may pool all their money together to help buy a needed device (Santana & Santana, 2001). Unfortunately, this approach is very limited for a family operating on a fixed income. The acquired piece of technology may come at the cost of multiple sacrifices and often cannot be repeated for multiple pieces of AT.

Recognition that AT-related advantages do not result in rewards for themselves or family members
It is important to realize that the AT-related advantages that seem obvious to Westerners may disappear when that same piece of technology is used in a different setting. Opportunities such as telecommuting become unavailable if there are no telephone lines or electrical outlets in the home of the person with the disability. If the consumer does obtain the AT device, there is also no guarantee that they will achieve all the AT-related advantages that were cited to them when they were acquiring the device. For example, if the environment in which the consumer lives has high unemployment, obtaining an adaptive piece of AT will not necessarily help them to get out into the workforce.

Current topics being researched

Presently, there are a few research projects being funded by NIDRR that are making a decisive effort to address minority groups and AT. These topics, along with the project names, were taken from the National Rehabilitation Information Center for Independence (NARIC). Examples of the topics being covered include:
• Developing, implementing and evaluating a responsive infrastructure and comprehensive plan that targets underrepresented and culturally diverse communities (Utah Alternative Financing Program for Assistive Technology);
• Eliminating barriers to obtaining AT by focusing on outreach activities to targeted groups (MonTECH; Louisiana Assistive Technology Access Network; Tennessee Technology Access Project)
• Identifying effective strategies for enhancing minority access to alterative funding programs for AT (Minority Outreach Program for Alternative Financing for Assistive Technology)

There are other projects that have stated goals of making AT available to all consumers, including the Rehabilitation Research and Training Center on Full Participation in Independent Living (Kansas) and the Multiple Sclerosis Rehabilitation Research and Training Center (Washington).

By examining the foci of these and other projects, it is clear there are many areas of need for minority consumers with disabilities, especially with reference to AT. There is little information available on this subject in comparison to general disability information. As Galvin states in her article (1997): "The needs are great among these various minority groups, but they have traditionally not had the same level of access to services. While there is little hard data available to document needs, the problem is well-recognized" (p. 57).

Why do we need more research?

With members of these groups being disabled at higher rates than their White counterparts, AT would seem to be high in demand by disabled members of these groups. Unfortunately, this is not the case. Factors such as lack of health insurance and low income contribute to lower AT use among these populations, because insurance and self-payment are among the most common methods of payment. According to a study done by Smart and Smart (1997), people who do not have health insurance see physicians less, and non-whites are less likely to be insured. Mills (2002) found that between 1999 and 2001, uninsured rates were as follows:
- 33.0% for Hispanics (of any race)
- 27.1% for American Indians and Alaska Natives,
- 19.2% for Blacks,
- 18.5% for Asians and Pacific Islanders, and
- 9.8% for non-Hispanic Whites (p. 7).

Private health insurance is one of the most common methods people use to obtain AT, through assessments and prescriptions, for example. For some, health insurance is tied to employment. The disabled individual may not be able to afford high insurance premiums on their income and may choose to go without an insurance plan because they do not qualify for social services. This is important because most individuals who need AT frequently get information about needed devices, how to obtain it, maintain it and use it from a medical professional (Abouhassan, 2001; Carlson, 2002).

Those who work with disabled persons from non-white ethnic backgrounds and their families recognize that the need for AT services and devices is there, but the disability community and policy makers must also make the commitment to apply the data. In a commentary on race and disability policy, Fujiura (2000) presents the following findings and recommendations concerning minority participation in the disability system:

1. Poverty is one of the main impediments to participation and advocacy;
2. Minority persons to not have full knowledge of and do not fully utilize the services and programs of nearby agencies;
3. There has been a failure to bring minority clients and professionals into the mainstream of the movement;
4. Although minorities are proportionately represented among employees of disability service programs, they are rarely represented in the highest categories of employment as professionals or in administrative leadership;
5. Leadership is essential to remediate these problems; the field needs to expand outreach and technical assistance; providers need to be sensitive to ethnic needs and sensitivities; and consumers need to be directly involved on boards and advisory committees, and in research. (p. 73)

Fujiura found this list has been cited and re-cited in documents for over twenty years and was taken from a report by the Bureau of Development Disabilities (now the U.S. Administration on Developmental Disabilities) in 1979. More information is needed because complicating factors to the low utilization of AT by these groups may be attributed to cultural practices, discrimination, prejudice and poor information dissemination.

Areas requiring more research

1. How can information be more accessible, appropriate and understandable for those of different linguistic and cultural backgrounds?
2. What are the implications of AT on family structures within various cultures?
3. What are the effects of AT on family structures within various cultures?
4. What types of AT would be ideal to these communities? What characteristics might it have?

5. How can AT and AT services be made to appear more complimentary rather than threatening to a traditional way of life?
6. What are some successfully explored methods of integrating AT into culturally diverse communities within the US? Are they replicable?
7. What current AT devices are seen as acceptable within the various ethnic minority communities?
8. What is the range of spiritual beliefs about disability and/or technology across various minority cultures?
9. Does AT make a disability more visible?
10. How has the lack of adequate health insurance contributed to accessing AT?
11. How have systems change efforts affected minorities with disabilities accessing AT?
12. Would AT be more acceptable in certain communities if it was viewed as a compliment to family care rather than a replacement?
13. Is there a perceived need for AT devices?

[1]According to the 2000 US Census, people who identify with the terms Hispanic or Latino are those who classify themselves as: Mexican, Puerto Rican, or Cuban, as well as other Spanish, Hispanic, or Latino. Origin can be viewed as the heritage, nationality group, lineage, or country of birth of the person, the person s parents or ancestors before their arrival in the United States. People who identify their origin as Spanish, Hispanic, or Latino may be of any race. (US Census Bureau, 2000).

SUCCESS STORY

Assistive Technology and Health Access

Corbett O'Toole

For many people, a visit to the physician is very routine: temperature is taken, a person is weighed…a general physical. But for people with disabilities, an examination can be very "un-routine" because hospital and clinical facilities are not accessible. Corbett O'Toole uses various mobility devices, including both manual and electric wheelchairs. In her visits to the physician, the height and the lack of side supports for the examination table have posed a big problem. Gynecological visits were no exception. It is dangerous for her to transfer to the table from her wheelchair and back because there is no support, and there is nothing to hold onto to make sure she does not fall off the table. This is also a problem with healthcare for her daughter, who also uses manual and electric wheelchairs as well as leg braces. It is very common for mother and daughter to not have their weight checked, even though this is a routine procedure, because there are no accessible scales. This is especially important for her daughter, because children's prescriptions are dosed by the child's weight. Obviously, without accessible examination equipment and facilities, a person's healthcare could be at-risk.

Once, by accident Corbett was given an examination room with a Welner Accessible Examination Table (http://ourworld.compuserve.com/homepages/ trish_and_john/examtabl.htm). She says, "It was heaven." For easier transfer to and from her wheelchair, the table was height adjustable so that it came down to the level of a wheelchair, and there were movable side arms. The arms could be placed up for transferring and down for holding onto while she was on the table. For gynecological examinations, there were thigh/calf pads (in addition to the regular foot stirrups) that help to support a woman's leg. These pads could be moved vertically and horizontally. The table was also slightly wider so a person could roll onto it and not fall off. Corbett describes her first visit with this table as the best health care experience of her life. These additions and adaptations made a safer and more comfortable physical and gynecological examination possible. Unfortunately, AT is not offered to patients in health care situations even when it is available. Corbett's gynecologist added a lowered table to her facilities, but her nurse still put her in an inaccessible room and never mentioned the accessible one was available. Corbett encourages others with disabilities to self-advocate. Ask for access. Although it is not easy to ask, the alternative is much worse. A person might never have access if they do not state their own needs.

Health care providers also need to become more proactive about the accessible features they have, including information such as their TDD numbers, availability of accessible equipment, and health care education in alternative formats. People that are newly disabled often do not know what things they need or what questions to ask.

Corbett suspects that if a basic "Here is the AT we have available for you-our valued patient" brochure was created and given to each patient, the use of AT in hospital and clinical settings would rise dramatically. Making health care accessible is more than just having the equipment and services. Accessible health care includes informing patients what devices and services are available.

Corbett O'Toole is the director of the Disabled Women's Alliance and has post-polio syndrome. Her daughter, Meecha, is 9 years old, in the third grade and has cerebral palsy.

CHAPTER 4

The Effectiveness of Assistive
Technology in Accessing
Health, Wellness, and Medical Care:
What we know now

By Tanis Doe, Ph.D. and Laura Hershey, B.A.

Introduction

Although access to health should be guaranteed to all — including basic
medical care, health information and education, health-promoting activities,
and health services of all kinds — it is denied to many people with
disabilities. Many different obstacles block disabled persons access to
health services and health activities. These obstacles include financial
hardship, insurance coverage limits, lack of awareness among health
practitioners, and many more barriers that are beyond the scope of this
review.

Physical and communication barriers are major factors limiting disabled
persons participation in health activities and use of health services. This
paper will describe *assistive technology* as a possible solution to some
barriers. It surveys existing literature on the use of assistive technology in
accessing health; describes conclusions of previous researchers; and
identifies gaps.

Other papers in this series will address assistive technologies that aim to
reduce impairments, such as prosthetic limbs or cochlear implants; devices
that assist in the management of disability-related functions, such as
catheters or seating cushions. Three other papers will examine the wide
range of assistive devices that aid in independent living, employment, or

function. This paper will focus more narrowly on the use of assistive technology in enabling disabled people to achieve equal access to medical care including doctor visits and hospitalization; to health maintenance including self-medication and monitoring of routine health signs; and to health-promoting activities such as exercise.

As defined by the Assistive Technology Act of 1998, the term *assistive technology* refers to "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities." (RESNA, 2002)

Assistive technology (AT) can help improve disabled people's access to health care in several ways. One way is for doctors' offices, hospitals, clinics, fitness centers, and other facilities to make their standard equipment accessible and available to disabled people, by adapting or enhancing them with devices or accessible features. Examples of this include adjustable examination tables, wheelchair-accessible mammography machines, adapted exercise equipment, or even health instructions provided in different formats.

Another way is to equip disabled people themselves with devices that they can use to surmount some of the barriers they face in pursuing health care, health activities, and health information. For example, blind people can independently monitor their heart rate, their blood glucose levels, etc., using devices which provide auditory feedback. Approaches from different perspectives recognize the complexity of health care barriers, involving the relationship of the *disabled* individual to the *disabling* environment. One engineer, who has studied technology and disability extensively, asserts: "Individual and environmental deficit modification need to go hand in hand." (Scherer, 1996, p. 75)

"The most important thing to recognize is that ultimately you and you alone are responsible for managing your own health.... Getting the most out of health care services requires you to be active and vocal in all aspects of health care" (Kailes, 1998). This paper will consider assistive technologies that empower people with disabilities to be active health care consumers.

Accessing Health

In a recent working document, *Healthy People with Disabilities 2010* health promotion for people with disabilities was defined as a four-part process:
- the promotion of healthy lifestyles and a healthy environment,
- the prevention of health complications (medical secondary conditions) and further disabling conditions,
- the preparation of the person with a disability to understand and monitor his or her own health and health care needs, and
- the promotion of opportunities for participation in commonly held life activities. (Public Health Service, 1998)

The goal of health care for individuals with disabilities is attaining and maintaining health and decreasing the occurrence of secondary conditions of disability. Individuals with disabilities use more health care services, accumulate more hospital days, and incur higher per capita medical expenditures than do non-disabled people. People with no activity limitations reported approximately four physician contacts per year; this figure doubled for those who had some activity limitation, five times as high for those unable to perform major life activities, and seven times as great for those needing help with instrumental activities of daily living (LaPlante,1993). Understanding the relationship between disability and health has implications for the public health agenda and the application of primary disease prevention strategies to the health of people with disabilities. This paper highlights various areas and activities within which assistive technology tools have been effective in enabling disabled people to pursue better health, and/or to enable health care providers to offer better access to their services.

Defining Effectiveness

Researchers have identified a number of different approaches to assistive technology outcomes research, respectively measuring efficacy (Does it work?), effectiveness (Does it work in naturally recurring conditions?), appropriateness (Does it work for a particular group of people?), and cost-effectiveness (Does it work as well as, or better than, something else?).

In defining effectiveness primarily in terms of cost-effectiveness, the

discussions tend to shift away from the disabled user of assistive technology, focusing instead on third parties paying for equipment and/or adaptations. In this case, questions about effectiveness are weighed in terms of investing in AT in order to reduce other expenses, or to increase revenues. Do frail elderly people using AT get sick less often, thus costing their insurance companies less for treatments and hospitalization? Do assistive devices in hospitals help to avoid costly lawsuits? Are physicians losing patients because they lack the technology necessary to serve people with disabilities?

Health, fitness, and medical care constitute large, powerful industries in the U.S. In this sense, *effectiveness* is measured in terms of profitability, and determinations are made by those who seek profits (influenced somewhat, perhaps, by laws and regulations). For example, Bennett reports that the owner of a Nautilus fitness club in Independence, Virginia, considered introducing equipment geared toward people with disabilities; but after doing "market research to define the extent of the need," he decided against the plan. Instead, he "decided to refocus on what it [the club] did best — [provide] strength equipment for able-bodied individuals." (Bennett, 1999)

In assessing the effectiveness of assistive technology, some researchers prefer to use instruments which measure "health-related quality of life" (HRQL). Some argue that this approach works best, because the emphasis on collecting subjective data from the patient's [*sic*] prospective parallels the importance of consumer involvement in assistive technology practice. This leads to the importance of measuring and using assistive technology user data as outcome measures (Pope & Tarlov, 1991).

Independence, Safety, and Health: Assistive Technology and Lowered Medical-Care Costs

Assistive technology "may reduce risk by allowing persons with a disability to modify their behavior in health enhancing ways.... [T]he appropriate application of assistive technology should be a risk reducing component in the person's overall health promotion plan." Various kinds of assistive technology, for example, can help to prevent secondary disabilities related to spinal cord injury. Secondary disabling conditions, and preventative technology, include: specialized cushions and seating systems to avoid skin breakdowns and decubitus ulcers, and cycling and functional electrical

stimulation to increase physical activity which promotes cardiovascular health (Kincaid & Marge, 1995).

AT research projects focusing on independent living have reached conclusions relevant to health and well being. One of the most comprehensive and widely referenced studies attempted to assess the impact of assistive technology on the health and independence of 104 home-based frail elderly persons living in western New York. The 52 individuals in the treatment group received evaluations followed by appropriate AT devices, and the 52 participants in the control group received only "usual care services." While both groups experienced declining functional ability and health over time, those that received AT showed fewer declines than did the control group, and also had lower health care costs. The participants who used assistive technology were less likely to be institutionalized, hospitalized, or visited by home nurses. A big factor in this trend was prevention of injuries.

People using walkers, canes, and other devices appeared to be less likely to fall and sustain major injuries. Serious falls accounted for four hospitalizations in the treatment group and 11 in the control group. The researchers also theorize that the reduced hospital costs "could also be related to increased feeling of responsibility for one's health care, and more interest ... in getting back home, resulting in shorter stays" (Mann, Ottenbacher, Fraas & Tomita, 1999).

Following Doctor's Orders: Using AT in Routine Medical Self-Care and Treatment

Technology has allowed many people with chronic illnesses to be treated effectively at home, rather than in medical facilities. Such devices can be difficult for disabled people to use for several reasons — complexity of operation, required dexterity, etc. However, assistive technology can enable people with different types of disabilities to use medical devices. An example is continuous ambulatory peritoneal dialysis (CAPD), a device for portable treatment for patients with kidney dysfunction. In 1993, nurses from an Indiana dialysis unit collaborated with engineers from a CAPD manufacturing firm, to design a single-handed assist device. This innovation was developed in response to the needs of an individual patient who had been injured in an accident, had memory loss, and could only use one hand.

The team modified the original assist device, adding slots and a swivel clamp to hold tubing and other parts securely in place, and suction cups for greater stability. In addition, one of the most effective strategies was an audiotape recording of step-by-step instructions for carrying out the procedure. The device and the audiotaped instructions proved highly effective: The patient completed her training in 26 days, and successfully carries out her own daily dialysis treatments (Berger, 1996).

Because home treatments — including mechanized procedures and medication regimens — usually require following written instructions and/or written feedback, some visually impaired people and others with print disabilities have been unable to effectively follow medical orders without assistance from others. The ability to self-administer medication is an important factor in staying healthy and independent. People with visual or perceptual impairments may have difficulty with written instructions on medication bottles and labels. Several assistive technology innovations have proven successful in enabling people to follow medication instructions without having to read printed material. For example, a device called the ScripTalk Talking Prescription System, manufactured by En-Vision America, Inc., uses a special label containing an embedded microchip. This "smart label" is printed and programmed by the pharmacy's computer system and contains all the prescription label information. At home, the patient uses a handheld ScripTalk Reader that speaks the pertinent prescription information such as the patient's name, drug name and strength, directions for use, and any special warnings. The system's potential effectiveness and importance has been recognized by *Popular Science* magazine, which named it one of the top 100 technological achievements of 2001. (Press releases at En-Vision America, Inc. 2001)

Another area in which technology is giving people better access to health-related self-care, while bypassing the need to be able to read print, is the crucial task of monitoring blood glucose levels. Diabetes can lead to blindness. "Diabetes is one of the leading causes of vision impairment in the United States. The National Eye Institute (May 2000) reports that 40-45% of the 10.5 million people diagnosed with diabetes have some degree of diabetic retinopathy; in 600,000-700,000 cases, it is severe enough to cause vision loss. As many as 24,000 people annually become blind from diabetic retinopathy. According to the Diabetes Control and Complications Trial (1993), up to a 76% reduction in the risk for diabetic retinopathy occurs with

more intensive diabetes management. Intensive management requires an increased frequency in insulin injections as well as in blood glucose monitoring. Visual impairment poses a significant challenge to the very tasks that are a prerequisite to maintaining well-being and health and avoiding further complications." (Sokol-McKay, 2001)

Successful management of diabetes requires daily blood glucose monitoring — which can be difficult or impossible for someone who is unable to read the digital displays on most blood glucose monitors. However, assistive technology is now available to grant access to this process and the crucial information it provides. "In the past decade, equipment manufacturers, diabetes educators, and visually impaired people have worked together to create several types of adaptive equipment and techniques. These have made independent self-monitoring of blood glucose a reality for visually impaired people. Today, most visually impaired people who have appropriate equipment and instruction are able to effectively monitor their own blood sugar." (Williams, 1999) Assistive devices for blood glucose monitoring include those with large-print meter displays and voice-adapted meters. A relatively new blood glucose monitoring device is the Accu-Chek Voicemate, developed by Roche Diagnostics-Boehringer Mannheim Corporation, in conjunction with Eli Lilly and Company, which uses speech synthesis to talk the user through insulin vial identification, test preparations and procedures, and results. One reviewer has rated it "the easiest meter for a blind diabetic to use, facilitating far more independence in diabetes self-management than was possible before." (Bryant, 1996)

Many other products are now available to enable blind and visually impaired people to monitor their own health and to comply with medical instructions. These products include: talking blood pressure meters; digital talking thermometers; and a device to enable a blind person to fill a syringe with insulin, by listening for a click which sounds at each increment. (NFB website, 2001)

For people with cognitive and/or psychiatric disabilities, the ability to follow a medication schedule may mean the difference between functioning well and independently, or facing recurrence or exacerbation of illness, even facing the possibility of institutionalization or other forms of coercion. While the assistive technology needs of people with mental disabilities have been largely overlooked, a few researchers have documented assistive

technology's potential to aid this group. In *Solutions: Assistive Technology for People with Hidden Disabilities* (Lee, 1999) a section on "Medication Devices" describes a variety of applications, some decidedly simple and low-tech, others ingeniously high-tech, which can support people in taking responsibility for their own medication schedules and dosages:

> "The Pill Dispenser, for example, opens like a book with 28 easy-to-load bins inside to hold enough pills for 4 dosages a day for a week or one dosage a day for a month. When needed, the correct pills are released into a cup at the push of a button."

> "Pill alarms, such as the Pill Alert, provide an alarm feature which can be set to ring at the time or times medication needs to be taken. Some automatically re-set to repeat the same countdown interval, have built-in water flasks, or have lights which identify the compartment that should be opened. Pill alarms can come pocket-sized or can even be housed in a wristwatch."

> "A more complex solution to help take medications at the right times and in the right dosages is the CompuMed Pill Alert automated medication dispenser which organizes a week's supply of pills and vitamins in a refillable plastic tray. The tray is locked into the easily programmed machine to deliver medications into a removable drawer. A buzzer sounds when you are to take the medication and continues to buzz until the pills are removed and the drawer is replaced. It dispenses dry oral medications and displays important instructions for all your medications." (Lee, 1999)

Equally important in medical self-care is being aware of one's own health issues, and maintaining regular and accurate communication with one's physician. For some people with mental disabilities, it can be extremely difficult to convey information to a doctor, and to process information given by a doctor. Technology has also been shown to be effective in bridging these barriers. Clinicians at the Institute for Cognitive Prosthetics in Bala Conoid, Pennsylvania, developed a computer-based program for a 41-year-old man who had sustained a severe brain injury three years earlier, and who had cognitive disabilities in the areas of memory, sequencing, generalization, and problem-solving.

Treatment sessions were conducted using a computer-based telerehabilitation method. A clinical team conducted 3 telerehabilitation treatment sessions per week with the patient. Treatment sessions generally focused on the use of the assistive technology to facilitate greater independence." One of the individual's identified functional problems, which were part of the project's focus, was "relaying detailed information to his physicians during medical appointments." The project was highly effective in strengthening the individual's ability to communicate important information to his doctor. After two half-hour training sessions, the clinical team reported, he "was independent to add to and print a file that he titled 'doctor information'. Follow-up data revealed he modified and printed this document two times a month for his appointments." (Cole et al., 2000)

Similarly, assistive technology can give people with disabilities access to mental health services, through "the emerging field of telepsychiatry." Proponents claim that telepsychiatry "delivers more than adequate mental health services to needy rural populations unable to access them any other way." Michael Flaum, MD, recently compared the experiences of two community mental health centers in rural Iowa. One center offered face-to-face mental health sessions to voluntary participants exclusively for a year while the other offered telepsychiatry. Then the two centers switched modes for a year. Surveys conducted afterward indicated patients had no preference for one venue over the other, nor were there differences found in clinical outcomes. (Gibbons, 2002)

Another researcher presented even more favorable findings at the annual meeting of the Academy of Psychosomatic Medicine in Palm Springs, California 2001. Don Hilty, Ph.D., of the University of California at Davis, reported treating patients with depression, anxiety, bipolar disorder and schizophrenia remotely. On a scale of 1 to 5, Dr. Hilty's patients gave the technology an average 4.5 score in terms of quality of care, transmission quality and "ability to speak freely." (Gibbons, 2002)

Training for Health: Pursuing a Personal Fitness Program

In general, people with disabilities show more health risk factors than do people without disabilities, and there is substantial research indicating these risk factors can be modified through regular physical activity. Health risk factors include lack of physical fitness, weight gain, poor nutrition, social

isolation, emotional dependence, depression, behavioral problems and family stress. (NCPAD) People with physical disabilities can be especially prone to developing secondary conditions, including obesity, pressure sores, infections and osteoporosis, which can cause illness and/or further disability (Rimmer, 2001). Physical immobility often leads to a sedentary lifestyle that can, itself, create secondary health problems. For example, spinal cord injury (SCI) results in multiple degenerative changes, such as skin breakdowns, that may be related to physical inactivity (Ragnarsson, 1988). In one study, physical inactivity was found to be a major contributing factor in the deteriorating physical health of persons with disabilities. (Coyle & Santiago as cited in Rimmer, Braddock & Pitetti, 1996). Physical exercise, in some cases, even rigorous exercise, is an avenue to health for some people with disabilities.

Assistive technology can give individuals much greater self-sufficiency in carrying out their personal fitness routines, and can thereby greatly enhance their motivation and efficacy, and confer significant health benefits (Domzal,1998). A documented story that illustrates the effectiveness of such equipment is that of Pam Fernandes, an elite athlete who is blind, resulting from complications of type I diabetes. Fernandes had been involved in many team sports as a nondisabled youngster. With the onset of her blindness and subsequent kidney failure at the age of 21 she could no longer exercise in the same manner as before. After a kidney transplant in 1987 she began to exercise enthusiastically, doing aerobic exercise and weight training. She also took up tandem cycling, and began learning about exercise physiology, including the importance of heart rate monitoring. However, she could not independently use a typical heart rate monitoring device, which used a digital display to provide feedback. In 1998 Fernandes discovered the HEARTalker Personal Trainer, a new product which delivered heart rate feedback verbally. "Training became more enjoyable because the feedback she was getting helped her train more effectively." She gained greater independence in her workout activities. Fernandes and other fitness experts strongly advocate use of this and similar devices by people with visual impairments, especially those with related diabetes. For these individuals, assistive technology can help facilitate exercise benefits such as cardiovascular fitness, weight loss, lower blood pressure, reduction of stress and depression (Mullooly & Fernandes, 2000).

Many Americans find resources and support for personal fitness regimens in commercial health clubs. These clubs, as places of public accommodation, are required by Title III of the Americans with Disabilities Act (ADA) to be accessible to disabled people, though not necessarily to provide equipment specially-designed to meet disabled people's needs. In any case, a recent study showed that the majority of people with mobility limitations felt that fitness centers typically do not have equipment that can accommodate them (Rimmer, 1999).

Most fitness club owners do not look for access features when purchasing exercise equipment. They tend to view people with disabilities as an insignificant market, distinct from their target market of healthy, able-bodied 19- to 35-year-olds. However, several advocates point out that relatively minor differences in a device's structure and settings can result in significant improvements in accessibility and effectiveness for people with a variety of disabilities. "To provide equipment for disabled members, club owners should look for machines that have positioned their resistance media or controls so there is not a long reach to make adjustments. Machines with electromagnetic or pneumatic resistance have buttons to change settings as the 'weight' is indicated on an electronic display or gauge. For some users, such as older adults and people with disabilities, it's important that resistance start at nearly zero and be changeable in small increments," points out one author. Also: "Treadmills should start very slowly for people who might require a more gradual return to normal gait speed. They shouldn't require users to step high to begin their exercise routine. And, belts a few inches wider than standard will allow ambulatory users to stay on easier." (Bennett, 1999)

These "new demands on fitness managers and professionals to make their facilities more 'disability friendly'" should be accommodated, given "the resources currently available to develop safe, effective programs," says another expert in disability and fitness. "This is a win-win situation for people with disabilities and fitness professionals." (Rimmer, 2001)

In addition to the adaptations to standard exercise equipment, described above, exercise equipment is being manufactured that incorporates universal designed features so people with a broad spectrum of strength and abilities can then use the equipment without reducing the equipment's usability or attractiveness for all exercisers (Kailes, 2000). Several different

companies have designed cycles, operated both by hand and by foot, to enable people with different degrees of paralysis and/or immobility to do passive and active exercising. For example, the Saratoga Cycle and the Colorado Sports Cycle can be powered by using handgrips, which provides upper-body exercise; and both can be fitted with foot pedals. On these machines, users with and without disabilities can get a cardiovascular workout. PowerTrainer cycles use two sets of gears — upper and lower — to provide both active and passive exercise capabilities: Manually rotating one set of gears causes the other set to rotate, thus exercising paralyzed limbs. One model of the PowerTrainer cycle also gives functional electrical stimulation, which helps in maintaining the tone on inactive quadriceps and hamstrings (Bennett, 1999).

A similar device, the "EX N'FLEX Arm/Leg machine," is produced in Canada. The manufacturer conducted one hospital study in Ontario to determine the machine's effectiveness in promoting the health of users. From September 1993 through September 1994, a group of 23 hospital patients used the EX N'FLEX regularly. Survey results demonstrated the following benefits: 100% of study participants had an increase in energy; 83% improved their balance; 48% developed better eye-hand coordination and/or better arm motion, hand control, or finger control; 70% showed improved mobility. (Note: No information is provided about this study's methods or authors.) A similar exercise device is the Neuromuscular electrical stimulation (NMES) leg cycle ergometer. A group of researchers conducted a study to determine if training two times per week on the NMES would improve cardiovascular fitness in persons with spinal cord injury. Eight males with SCI were tested over 24 NMES leg cycle training sessions over 12 weeks. Resistance was adjusted each training session to allow for 30 total minutes of exercise. Results showed peak oxygen uptake (indicator of cardiovascular fitness) increased 10% and peak power output (indicator of leg muscle endurance/strength) increased 25% as a result of the NMES leg cycle training (Hooker, Scremin, Mutton, Kunkel & Cagle, 1995).

Many recent studies have investigated the results of exercising, in combination with electrical stimulation, for people with spinal cord injuries (SCI). In one study, 10 individuals with SCI exercised for a year using an electrically induced computerized feedback controlled cycle ergometer. They trained for 30 minutes, up to three times a week. The gluteal, hamstring and quadriceps muscles were stimulated via electrodes placed on the skin over

their motor points. Results showed an increase in endurance and oxygen uptake, and decreased muscle atrophy and fatigue (Mohr et al., 1997).

A 1992 study tested the physiologic training effects of functional electrical stimulation leg cycle ergometer (FES-LCE) exercise in persons with spinal cord injury (SCI) who were previously untrained in this activity. Ten persons with quadriplegia (C5 to C7) and eight with paraplegia (T4 to T11) performed FES-LCE training on an ERGYS-I ergometer 10 to 30 minutes per day, two or three days per week for 12 to 16 weeks. Each participant completed discontinuous graded FES-LCE and arm crank ergometer (ACE) tests before and after training for determinations of peak lower and upper extremity metabolic, pulmonary, and hemodynamic responses. Compared with pretraining, this group exhibited significantly (p less than or equal to .05) higher post-training oxygen uptake, pulmonary ventilation, heart rate, and cardiac output. The researchers found no significant changes in peak stroke volume, mean arterial pressure, or arteriovenous oxygen difference (Hooker et al., 1992).

Another study recruited 30 SCI subjects to participate in an exercise program involving functional electrical stimulation of muscles of the lower extremities. Researchers noted increased strength, endurance, and bulk in the stimulated muscles. The participants were able to perform a greater amount of work on a lower extremity ergometer, both per unit of time and per length of time, indicating a training effect. Participants also increased their aerobic metabolism and their muscle density, and slowed their muscle contractions (Ragnarsson, 1988). In another study, FES-induced exercise led to increased exercise tolerance, muscle strength and endurance, thigh muscle area, joint range of motion, functional capabilities and general wellbeing. (Bremmer et al., 1992) Still another study of exercise enhanced by functional electrical simulation (FES) showed improvements in cardiovascular and musculoskeletal fitness among 10 males and two females aged 16 to 46 years, seven with paraplegia and five with quadriplegia, ranging from three months to 22 years post-injury. Specifically, tidal volume, oxygen consumption, respiratory quotient, and thigh girths increased significantly. Based on these improvements and the absence of any serious complications, this team of researchers concluded "that FES is an effective and safe method to improve cardiovascular and musculoskeletal fitness in individuals with spinal cord injury." (Arnold, McVey, Farrell, Deurloo & Grasso, 1992)

Equipment which allows hybrid exercise (leg plus arm) appears to be more effective in improving participants' health than devices that permit FES leg cycle training alone, according to a 1997 research project. Eleven men with complete spinal cord injury, ages 20 to 50, engaged in three phases of exercise training. The test "demonstrated that hybrid exercise performed twice a week provided sufficient intensity to improve aerobic capacity and provide a medium whereby patients with SCI can burn more calories than via FES-LCE alone. This has important implications for improving the health and fitness levels of individuals with SCI and may ultimately reduce their risk of cardiovascular disease," the researchers concluded (Mutton et al., 1997).

Children can also reap health benefits from physical exercise. Experts have developed techniques for involving disabled children in exercise programs, often incorporating assistive technology ranging from very low-tech to high-tech. "Many protocols designed for nondisabled children can be used directly or with minimal adaptations with children who have poor hand dexterity (i.e., cerebral palsy) using Velcro straps, cuffs, wrist and ankle weights, adapted benches, and standard training equipment." Children with disabilities can also effectively participate in muscular strength tests and endurance tests using special equipment such as a low chin-up bar that can be placed on the floor for children who cannot stand (Rimmer & Damiano, 2002).

Clinics Accommodating Disabled Patients Using Assistive Technology

As places of public accommodation, clinics and doctors' offices are required to provide auxiliary aids and services, including Braille materials, large-print materials, video and audio tapes, assistive listening devices, and computers when necessary to effectively communicate with patients with disabilities. Yet relatively few studies have attempted to determine the degree to which private medical facilities are accessible, in compliance with the ADA (Grabois, Nosek, & Rossi, 1999). Those few, however, indicate that while some progress has been made in accommodating clients with disabilities, more work needs to be done. These studies also point out that assistive technology is a key component in creating access.

A good example of assistive technology in a clinic setting is the "Welner Table," which offers universal accessibility for people with physical disabilities. Sandra Welner, M.D., responded to patients with disabilities who

expressed the need for "an accessible table, one that provides security, comfort, safety, flexibility and stability.... I incorporated all these features in the design of my universally accessible examination table for people with all abilities and limitations." The examination table lowers to wheelchair height to allow for easy transfers. Interchangeable foot attachments allow for choice between regular gynecologic stirrups and custom-designed leg holders that encase the whole foot with soft cushioning and security straps. These foot-leg boot supports can adjust to different degrees of spasticity, contracture, and limited range. The table can accommodate different leg lengths, different knee flexion/extension capacity, and different hip joints abduction/adduction capabilities. While no scientific research could be found to document the effectiveness of the accessible exam table, disabled people and disability advocates have universally lauded the table and its inventor (Disabled Parents Online, 2001).

A cornerstone of women's health care is access to regular mammograms, beginning around age 40. This diagnostic service is unavailable to many physically disabled women. One piece of technology offering access to mammograms is called the Bennett Contour Mammography System. The Bennett system can be adjusted so patients do not need to stand during the mammography process. Other technologies are currently in development, to improve breast health for disabled women. For example, three-dimensional ultrasound techniques to scan for breast tumors are under study (Welner, 1999). Additional efforts include work on imaging technology, such as hand-held equipment that could allow for in-home mammography. "There is the possibility in our lifetime of remote-site treatment." (Jones, 1999)

There are no national and little state surveys on accessibility at health care facilities, so it is difficult to gauge how available accessible equipment, such as adjustable mammography machines and exam tables, is on a national scale (Haran, 2000).

The intention of accessible technology, unfortunately, does not guarantee its effective use. One group of researchers surveyed 62 general practitioners, family practitioners, internists, and obstetrician-gynecologists, inquiring about a wide range of access issues — attitudinal, programmatic, and physical. Among other things, the questionnaire asked what kinds of auxiliary aids and services the physicians provided to patients with physical disabilities. Responses involving assistive technology included: audio

recordings (15%); videotapes with captioning (8.5%); telephones compatible with hearing aids (5%); telecommunication relay services (5%); and a typewriter or computer for the hearing impaired (3%). In addition, 39% of respondents had used or purchased an adjustable-height examination table; 13% had used or purchased a padded examination table the height of a wheelchair seat; 2% had used or purchased a platform or sitting scale. However, 18% of the primary care physicians in this study stated that they were unable to serve some patients with disabilities. Among the reasons for the inability to serve patients with physical impairments was inaccessible equipment (Grabois et al., 1999).

Another study addressed the perception of accessibility, as reported by clinic managers, versus actual accessibility in healthcare clinics in a Midwestern metropolitan area for persons using wheelchairs. This survey revealed that only 17.5% of the sites had an examination table that could be lowered to a standard manual wheelchair-seat height. Although a person using a wheelchair would be able to enter the examination room, 82.5% of the sites would require that the person be physically transferred. Even worse, the clinic staffs could not even provide accurate information about the availability of assistive technology such as adjustable examination tables. "Almost 38% of the sites reported that their examination table could be lowered to wheelchair level (21 in.); however, in actuality, only 17.5% had such an examination table. One did not know that its examination table could be lowered to wheelchair level" (Sanchez et al., 2000).

The ADA and the Code of Federal Regulations currently have no accessibility standards addressing equipment in physicians' offices. The Department of Justice had proposed that newly purchased furniture and equipment used in public accommodations be accessible, but the rule was never made final. Several researchers have urged primary care physicians to consider going beyond the requirements of the ADA and making their office more ideally suited to their patients with physical disabilities (Gill, 1999; Grabois et al., 1999). Says one researcher, "The ideal office for patients with disabilities will have an adjustable-height examination table, a platform or sitting scale, padded tables, and a staff able to properly assist patients with disabilities." (Grabois et al., 1999)

There are a number of anecdotal reports attesting to the increased confidence and satisfaction disabled people feel when their health care

providers create welcoming environments through assistive technology and other accommodations. Disabled women's health advocate Carol Gill, for example, described a friend calling to tell her about "a great afternoon" the day before. What was so great, Gill asked her friend? "She had gone to a gynecologist for a pelvic exam — hardly most women's idea of fun! What she found so exciting, though, was the fact that after 20 years of such exams, she had found a gynecological clinic specializing in access for women with disabilities and had felt acknowledged as a woman for the first time. She was effusive about the accessible examining chair, the discreet and respectful assistance she received, and the doctor who allowed her to remain in control and who encouraged her to watch the exam in a mirror." (Gill, 1996, p.23)

Financially accessible?

Even the most impressive, attractive technology may be ineffective in the wrong context. For example, the Chicago Tribune recently published an expose about a company which charges Illinois Medicaid $2000 per family for an online service designed to monitor the condition of sick children and to educate parents — even though three-quarters of those families don't own a computer, and don't have access to the Internet. The service allows parents to see their hospitalized children through an Internet hookup, and also trains parents to use simple medical devices and perform basic care techniques, such as controlling infections. Company executives cite a clinical trial conducted at Beth Israel Deaconess Medical Center in Boston, which concluded that the program enabled hospitals to discharge infants more quickly. This research appears to demonstrate the effectiveness of the monitoring program, but its methods and thus its conclusions may have been flawed: The study only involved families who had computers. Said one critical state legislator: "If the goal is to provide lower-income parents with greater access to their infant children in hospitals, then it would be far less expensive to pay for cab fare every day than to throw this money into a relative luxury, such as viewing your children over the Internet." (Berens & Long, 2002)

Increasingly, funding is available to purchase assistive technology for use in education, employment and, to a lesser degree, independent living. Funding for assistive technology for access to health care is somewhat more problematic. This is apparent in the dearth of literature addressing these

specific needs. Lengthy articles are available about how to obtain funding for devices used in school (IDEA requirements); and for use on the job (Vocational Rehabilitation, impairment-related work expenses as defined by Social Security, PASS plans, etc.) No research has focused specifically on how to obtain funding for assistive technology for any of
the uses described in this paper. However, a strategic approach to obtaining such funding would focus on the "medical necessity" of the particular device, thus increasing the likelihood of payment through Medicaid, Medicare, or private insurance.

Access and Accommodation: Using AT to Improve Accessibility of Medical Facilities

Assistive technology is an important, empowering factor for disabled people. Nowhere is it more crucial than in a medical setting such as a hospital emergency room. This is especially true for patients who are deaf or hearing-impaired "Auxiliary aids and services are often needed to provide safe and effective medical treatment. Without these aids and services, medical staff run the grave risk of not understanding the patient's symptoms, misdiagnosing the patient's medical problem, and prescribing inadequate or even harmful treatment. Similarly, patients may not understand medical instructions and warnings or prescription guidelines." (National Association of the Deaf Law Center, n.d.)

People with deafness, hearing impairments, or speech impairments frequently encounter barriers when they go to the hospital. Frequently, they must interact with physicians, nurses, and other staff who are unable to communicate with them, for a variety of reasons: Staff may not know sign language, or may be uncomfortable with unusual speech patterns. It is vital that qualified sign language interpreters be available in hospitals for deaf people who use this mode of communication; however, assistive technology offers another crucial method of access and accommodation.

The Health Care Financing Administration created a panel to develop professional standards, to apply across all health care settings, ensuring quality of care for patients with hearing impairments. Panel member Philip Zazove, MD, a clinical associate professor of family medicine at the University of Michigan at Ann Arbor, stated, "Even people with mild hearing loss have problems accessing health care." The panel favorably referenced

the Deaf Access Program at Mount Sinai Health System in Chicago, where "Accommodations have been made throughout the hospital for deaf patients and families. There's a public TDD/TTY phone in the lobby. Such phones translate conversation into words appearing on a lighted screen, and an attached keyboard allows a user to type back responses. All televisions are equipped with closed captioning. Bedside TDD/TTY, telephone amplifiers and other assisted-listening devices are available on request" (Shelton, 2000).

Both public and private hospitals and health care facilities must provide their services to people with disabilities in a nondiscriminatory manner. The provision of auxiliary aids and services, including assistive technologies designed for effective communication, are a key strategy in complying with the requirements of the Americans with Disabilities Act (ADA) (Leuchovius, n.d.).

The auxiliary aid requirement is flexible, and the health care provider can choose among various available technologies as long as the result is effective communication for the deaf or hard of hearing individual. Here, effectiveness must be determined with the input of the disabled person. "A deaf or hard of hearing person knows best which auxiliary aid or service will achieve effective communication with his or her health care provider. The Justice Department expects that the health care provider will consult with the person and consider carefully his or her self-assessed communication needs before acquiring a particular aid or service. 56 Fed. Reg. at 35566-67." (National Association of the Deaf Law Center, n.d.)

Recognizing the importance and effectiveness of assistive technology in hospitals, the United States Department of Justice has issued several directives mandating its availability in hospital settings. In 1998, in response to a complaint filed by deaf patients and deaf advocacy groups, a group of hospitals in Connecticut was ordered to immediately provide to hearing-impaired patients and their companions assistive technology and other "appropriate auxiliary aids and services that may be necessary for effective communication." Among the technologies listed in the Consent Decree are "assistive listening systems, and computer-assisted real time transcription services." The order also references of the language of the ADA itself, which defines the term "appropriate auxiliary aids and services" as including "...computer-assisted real time transcription services, written materials,

telephone handset amplifiers, assistive listening devices, assistive listening systems, telephones compatible with hearing aids, closed caption decoders, open and closed captioning, and TTY's. 28 C.F.R. § 35.104; 28 C.F.R. §36.303." (Consent Decree, 1998)

The Department of Justice (DOJ) has also provided technical assistance and even tools. In 2000, the DOJ distributed packets of "pictograms" to hospitals in more than 80 cities across the country to help medical personnel interact with patients who are deaf or hard of hearing. The notebooks of pictograms illustrate phrases using sign language with captions written in English below the pictogram. Hospital staff can look up a phrase in English and point to the phrase in the notebook, and then show the pictogram to the deaf person in order to communicate. (DOJ Press Release, 2000)

Assistive technology can also give more control and safety to physically disabled people who must be hospitalized. Such patients often have difficulty functioning independently, because they are unable to perform tasks such as operating beds and televisions, calling for nurses, and so on. Environmental control systems (ECS) are one type of assistive technology applications which can enable people to perform some of these functions, providing they are set up appropriately to the individual and to the environment. Some practitioners consider the availability of assistive technology in hospital settings highly effective and desirable. For example, two rehabilitation engineers assert (but do not demonstrate) that the availability of ECS to hospital patients who are disabled confers a number of benefits, including "improved self-esteem, reduced feeling of helplessness, improved quality of life, decreased need for paid attendants, and reduced demands placed on family members and caregivers." (Satchell & Lara, 2001, p. 138) In addition to increasing individuals' access and functioning while in the hospital, the use of ECS during hospitalization may encourage individuals to utilize ECS at home, after discharge, because it allows for familiarization, training, and evaluation (Satchell & Lara, 2001, p. 138).

The effectiveness of environmental control systems in hospital settings depends heavily on selecting, designing, and adapting these systems to perform in that particular environment. "Special issues involved in hospital ECS applications include widely varying user abilities, numerous health care providers interacting with the ECS, and electrical interference considerations. These issues have a significant influence on the design of

hospital based ECS." (Satchell & Lara, 2001, p. 138) Some aspects of a hospital setting would render certain types of ECS ineffective enough to rule them out entirely. For example, voice-recognition interfaces, while effective in many home environments, are not recommended in hospital settings because of noise interference (such as equipment alarms), and because acutely ill patients may not be able to produce consistent voice patterns due to fatigue, mechanical ventilation, or the effects of medication. (Satchell & Lara, 2001, p. 139)

Other recommendations for maximizing the effectiveness of ECS assistive technology applications in hospitals include the following:
- A stand-alone ECS is preferable to a computer-based ECS, due to considerations of mobility, durability, and simplicity.
- Control signal transmission should be through direct wiring, to avoid possible interference with other equipment.
- Modularity is an important design criteria, allowing just the amount of control the individual wants, needs, and can handle without becoming overwhelmed.
- User interfaces should be reliable, repeatable, and able to accommodate people with a variety of disabling conditions. Switches should be easy to position.
- Labels and displays should be clear, simple, and easy to understand, and should provide information in a variety of modes, including visual and audio.
- Mounting systems should be simple, secure, and durable.

"A versatile ECS that meets the criteria discussed above will provide patients with a single system that has the ability to meet their specific and changing needs throughout the duration of their stay thereby maximizing their level of independence." (Satchell & Lara, 2001, p. 140)

Conclusion: Gaps in the Research

Assistive technologies offer important bridges over the barriers facing disabled people in accessing health care. Both disabled consumers of health care services, and the providers of those services, can benefit immensely from access to reliable, appropriate, quality-of-life-enhancing, user-friendly, effective assistive technology.

The effectiveness of such technologies, and their widespread use, could be increased significantly with more available knowledge about the impact of various technologies in health care settings. To date, little research has examined health-care-related uses of assistive technology. As a result, consumers must rely largely upon word-of-mouth reports from other consumers, as well as on the self-serving claims of manufacturers.

Some of the questions that still need to be researched include:

1. Do people with disabilities who have access to specific technologies become more active, assertive, empowered managers of their own health care?
2. Do specific assistive technologies help disabled consumers achieve greater health and well being?
3. Do users of assistive technology have fewer health problems?
4. Can assistive technology be used to identify at-risk individuals and to involve consumers in regimens to prevent secondary conditions?
5. Does the availability of assistive technology in hospitals, clinics, physicians' offices, fitness centers, and other health care settings lead to more successful health outcomes for consumers served by those facilities?
6. Do health care providers understand the importance and effectiveness of assistive technology?
7. Do they make assistive technology available to their consumers? And do they know how to use the technology they possess effectively?
8. Who funds the assistive technology at the individual and services levels?
9. What technology interventions maximize physical, cognitive, sensory and emotional functioning for individuals with disabilities, taking into account aging, environment, emerging disabilities and health care reform?

10. What is the impact of changes at the medical rehabilitation and assistive technology industry level on access and outcomes for people with disabilities?
11. What other questions need to be asked? What are the current priorities?

Research on the above questions should be carried out rigorously, and with significant input from, and direction by, people with disabilities. NIDRR supports the use of participatory action research and use of the new paradigm of disability that integrates the individual and the environment to produce 'disability'. If you have comments, suggestions, additions or ideas for important research topics please contact the CFILC Community Research for Assistive Technology project.

SUCCESS STORY

Assistive Technology and Function

Kyle Glozier

Kyle Glozier is a disabled activist that gained fame by making a speech for the Democratic National Convention in 2000. He is a seventeen-year-old junior in high school who has his sights set on Temple University in either journalism or law. Kyle has cerebral palsy and cystic fibrosis. He also has a visual impairment but says that it's not a big deal. "The doctors say you are different. I say what is in your heart that counts. If you are the parent of a disabled child and you are disabled, that too if you loved that child you would find a way to overcome what the professionals say."

Kyle uses a Pathfinder communication aid that was bought through his school. He started using a communication device at age 5 as well as using sign language and his voice. Before he had a communication device he was frustrated. Not being able to express feelings clearly often led other people to underestimate his intelligence. The Pathfinder allows more people to understand him.

As advice for others considering AT Kyle says:

AT is there and you need to use if because if you don't you are trapped at home of in a hospital. I don't think of a wheelchair or a walker as being Assistive Technology. I think it is an extension of your body, like your leg.

Kyle also uses a power wheelchair. He says it is important to test your wheelchair and see how it works. When your friends are going to the mall you want your chair to be able to keep up with them. During a 4-5 month period when he didn't have a power chair Kyle experienced the most difficult time in his life. Finally when he got his power chair in Washington DC he made his mother run all over the city going sightseeing.

Kyle's mother, Laura, also suggested that although some people do not want to be seen as disabled they can be more independent with technology like a wheelchair than if they had to walk. She said that disability touches everyone at some point in life.

CHAPTER 4

The Effectiveness of Assistive Technology for Access and Function: What we know now

By Sarah Hall, Ph.D., Tanis Doe, Ph.D., and Amy Noakes, B.S.

Introduction

Assistive Technology has helped individuals with disabilities achieve and maintain full access and function in their homes and community. Technology for access includes public and private spaces and uses: from digital telephones and their usage by non-digital hearing aid wearers to stair glides for seniors who do not want to move out of their home with stairs. When people first acquire a disability they often need appropriate equipment. Where do I find information about available equipment that can help me hear again, participate in my family life, and get out in the community? What is the impact on family members and assistance providers? What are the barriers to accessing AT? This paper will focus on how assistive technology is being used to meet the needs of individuals with disabilities and discuss barriers to access, function and independence. "In California, more than six million people with disabilities could benefit by using technology to assist them in their daily lives, unfortunately, most of them go without access to that technology" (Alliance for Technology Access, 1999).

Relevant Legislation

The Telecommunications Act of 1996, an update of the Communications Act of 1934, requires manufacturers to ensure equipment is accessible to and usable by individuals with disabilities and/or compatible with peripheral devices commonly used by individuals with disabilities to achieve access. The Act also regulates video programming accessibility, such as closed captioning and audio video description.

The Television Decoder Circuitry Act of 1990 requires all televisions with 13" screens or larger sold or manufactured after July 1993 to be equipped with captioning decoder circuitry. This eliminates the need for a separate decoder for individuals who need captioning. The Act also applies to personal computer peripherals that include TV capability.

Telecommunications Accessibility Enhancement Act of 1988 established the Federal Relay Service and required the Federal telecommunications system to be accessible to employees and public.

Hearing Aid Compatibility Act of 1988 requires all telephones sold or manufactured in the United States to be hearing aid compatible and recently added a volume control requirement.

The Technology-Related Assistance for Individuals with Disabilities Act (1988), known as the Tech Act, endorsed the benefit of technology for individuals with disabilities and echoed the consensus that there was a lack of information, access and training available for potential consumers. The Tech Act established state programs to enhance the support services provided to people with disabilities in their use of technology.

Reauthorized and amended periodically, the Rehabilitation Act requires electronic information and technology purchased by the Federal government to be accessible, and obligates federal agencies to address accessibility in their programs (Section 508 of the Rehabilitation Act, 1999).

Definitions:

Assistive device / Assistive technology: "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 the functional capabilities of individuals with disabilities" (The Technology-Related Assistance for Individuals with Disabilities Act of 1988).

Functional Skills: "Those skills that allow the individual to have control in the environment with the least amount of assistance from others." (Beigel, 2000) Mobility: The ability to travel safely and efficiently from one place to another (Smith, 2001)

Universal Design: "The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design". (The Center for Universal Design, 1997).

Types of Disabilities & Equipment

In the United States, individuals with disabilities comprise our largest minority. Approximately 54 million people in this country have some level of disability and 26 million have a severe disability (The Center for Universal Design, 1997). Individuals with sensory, physical and/or cognitive disabilities face substantial barriers to function and social integration. For these individuals, AT assists them in activities of daily living and provides a critical link to the world in which they live. "It is difficult to overstate the contributions assistive technology is making in the quality of life for people with disabilities" (Parette & Brotherson, 1996). However, of the approximately 6.6 million individuals with disabilities in California, only 1.7 million use some type of assistive technology (Alliance for Technology Access, 1999).

Assistive Technology for Hearing

Approximately twenty one million Americans have some degree of hearing loss (Smith, 2001). Assistive devices for hard of hearing individuals include those used for listening, telecommunications, speech-to-text translations, and alerting. Compared with other disability groups, elders with hearing disabilities have the highest rate of dissatisfaction with assistive devices they own (dissatisfied with 32 percent of devices). "This rate of dissatisfaction rose to 60% when only hearing devices were considered" (Mann, 1995). Both the use of partial hearing and the extent to which an individual can use other sensory modes should be taken into consideration when making decisions about appropriate AT to improve access and function.

Assistive Listening Devices (ALDs)
Hearing aids are the most commonly used electronic device. Conventional hearing aids use analog components and may be worn behind the ear, in the ear or in the ear canal. Traditional hearing aids amplify all sounds equally and because of this background noise is problematic for the user. In response, hearing aids using digital components have been developed. Although costly, they have the capacity to block out background noise and allow for programming individual amplification based on a person's hearing

loss profile. A research priority of NIDRR is the development and evaluation of digital hearing aids to enhance speech intelligibility and increase the compatibility of hearing aids with electronic devices (computers) and telecommunication systems. Currently, there are interface problems between hearing aids and various wireless technologies, such as cellular telephones. Telecoils or induction coils are an added option on many hearing aids and can be used to reduce electromagnetic interference common with the use of assistive listening devices. Telecoils increase access to telephones, audio loops and other frequency modulated (FM) transmission devices. FM transmission devices, such as auditory trainers and audio loops are used to direct sounds directly to the listener's ear and block out background noise. However, the overuse of full spectrum sounds is presenting problems in the use of assistive devices and could potentially effect the quality of FM listening systems (http://www.connsensebulletin.com/action.html). Since the passage of ADA, audio loops have been installed in many public arenas, including airports, churches and theaters. Assistive devices may be personalized and portable, but can also be established in rooms and locations to benefit larger numbers of people.

Telecommunication Devices
Assistive devices to improve communication include captions, text and digital telephones, Wyndtell pagers and relay services. As a result of the Television Decoder Circuitry Act (1993), captions are viewable on all TVs. Prior to 1993, only 10% of deaf and hard of hearing individuals had access to closed captions due to the cost of a separate decoder (Sulzberger, 1990). Since open captions are unpopular with the general public, most movies shown in theaters do not have visible captioning. Rear Window Captioning (RWC) attempts to satisfy both the deaf/hard of hearing and hearing public. RWC projects captions onto a clear plastic screen attached to selected theater seats (Stanton, 1999). This same type of technology has also become useful for public speakers' notes.

Text telephones (TTY) provide displayed alphanumeric messages and are now available in portable, battery-operated and cellular versions. Some devices have the ability to take messages, deliver pre-set messages and common phrases. A voice recording alerting the use of a TTY is also available. The telecommunications relay service (TRS), required in all states by the Federal Communications Commission, allows anyone using a TTY to

communicate with someone using a standard telephone through the services of a trained communications assistant (operator). The voice carry over (VCO) option allows individuals to use their voice to send messages, but receive communication through text. This option is popular among late-deafened and oral deaf users who want to speak for themselves on phone calls. Answering machines that take messages in either format are also available. Secure pay TTY's in public places allow access to telephones by hearing and deaf/hard of hearing individuals. New technology in the form of the Video TTY Videophone allows a listener to see sign language, read lips or choose to type. This is popular with deaf families and people who have difficulty using English.

Interface Devices
For individuals with partial hearing loss, universal design features of some computers allow the user to change the system beep to a sound that is more audible and/or pair visual cues simultaneously with auditory cues.   Using headphones or a loop plug helps some people with computer audio and can be useful for language learning when enough residual hearing exists. The iCommunicator (www.teachthedeaf.com) converts speech-to-text, speech-to-sign language, speech-to-computer-generated voice and text-to-computer-generated voice in real time. This multimodal presentation of information helps individuals with hearing disabilities as well as those with other disabilities involving speech, language or hearing.

Alerting Devices
Alerting devices use sight, sound or vibration to make individuals who are deaf, deaf-blind or hard of hearing aware of important sounds. Flashing lights or vibrations can signal doorbells, telephones, timers or alarm clocks.

> "The day might start with a vibrating alarm clock that shakes the bed and the morning news on TV with captions running along the bottom of the screen. Lights flashing wildly in the kitchen signal burnt toast again. Different flashing light patterns indicate the doorbell is ringing." (Smith, 2001)

Assistive Technology for Vision

Approximately 5 million people in the United States have severe visual disabilities, however the vast majority are over the age of 65 (Smith, 2001).

"Older people with visual disabilities use a high number of assistive devices but still demonstrate a lack of knowledge of devices available on the market, and express a need for additional devices" (Mann, 1995). Many of the computer applications used with blind and low vision individuals necessitate state-of-the-art computers that are able to interface with assistive devices such as speech synthesizers or large-print displays (Lindsey, 2000). These are more frequently used by younger blind people, particularly students.

Other items that increase access for individuals with vision disabilities are part of mainstream society and are widely available, such as magnifying glasses, large-print and audiotaped books. As with other sensory disabilities, the ability of an individual to use partial vision and/or alternative sensory modes to compensate for vision loss should be considered when making decisions about AT. Many people do not consider vision loss a disabling condition until they discontinue being able to cope with glasses, light adjustments and easily available devices.

Access to Information
Access to reading has been accomplished using numerous technologies including large-print displays, speech synthesis, tactile devices, and Braille applications. For individuals with functional sight, large-print displays can be generated using closed-circuit television (CCTV) or word processing programs. The Magni-Cam hooks up to a television and the user rolls the handheld camera horizontally over the text. This technology allows immediate and easy access to a wide range of materials, but the reduction in material displayed on the screen may make it difficult to read. Other visual aids for individuals who are partially sighted, such as magnifiers (optical and electronic), are less expensive than large-print displays and can be used in much the same way as they are with print. Another audio aid, audiodescription, uses FM transmission in theaters and the extra sound track in stereo televisions to narrate the visual cues and nonverbal information presented on the screen. Some movies available for rent and on TV also provide this service, but it is still infrequently publicized.

There are numerous adaptive technologies available that use speech output systems, allowing users to access a wide variety of software and information. Text-to-speech engines can verbalize keystrokes and read information displayed on the screen, as well as convert words stored in memory to speech. Computerized letter recognition (Optical Character

Recognition, OCR) programs in addition to converting printed information to digital text can also provide output in synthesized speech, Braille or tactile signals. The Kurzweil Reader (http://www.kurzweiledu.com) is a personal computer and reading system that converts digital text to speech or Braille. It also allows the reader to select the rate and pitch of the speech generated. SoftVoice (http://www.text2speech.com/) and Eloquence (http://www.voicerecognition.com/) are text-to-speech engines that convert English text and other languages into real time speech.

Another type of speech engine, Speech recognition, has improved substantially during the past decade and allows the user to access the computer using verbal commands. Products such as Naturally Speaking (Dragon Systems, Inc.) and Via Voice (http://www.ibm.com) allow users to speak in a continuous rhythm rather than having to pause after every word. This type of "hands-free" alternative for controlling input is attractive to users with visual and physical disabilities. However, the effectiveness of any voice recognition system is influenced by the capabilities of both the user and the software system. Some people with significant accents or speech differences find the programs frustrating and inadequate.

Lastly, tactile aids are the preferred method of reading for some individuals with visual disabilities. Deaf-blind people are among the minority of people who do not use audio or speech synthesizing to access reading. Access to Braille versions of texts is improving as reading systems, such as the Kurzweil and personal computers are able to print Braille. Some printers (American Thermoform) can produce Braille and print on the same page. An individual may use a personal computer to change text to Braille and then print a hard copy of the information. Refreshable or paperless Braille is a tactile system that uses a series of pins that are raised or lowered to form Braille characters (Lindsey, 2001).

Technology for Mobility

Traditional orientation and mobility tools include canes, guide dogs, tactile maps, and sighted readers. Advances in mobility aids include Braille displays and devices, sonar canes, sonic guides, voicing or talking sign devices, intersection signalization controls, and dynamic tactile displays.

Audio and tactile maps enhance mobility of blind and visually impaired users by providing information about travel routes or destinations. They allow a user to access information about their surroundings without having to rely on a sighted person for details. Tactile maps may provide an overview of a city, state or country or details about a regular route to work or the bus. They can be created using American Thermoform's Swell Form Graphics Machine II (Horsfall, 1997).   Atlas, a talking digital map, conveys not only addresses and intersections, but also distance, points of interest, and directions to a designation. The Sendero Group (http://www.senderogroup.com) combined talking map software with real-time location information using Global Positioning System (GPS) technology. GPS-Talk allows the user to independently access information about location, route, and speed of travel, as well as landmarks and other relevant information about an area. However, this new technology is not without obstacles and may be difficult for some users, particularly pedestrians, as GPS works better in vehicles (http://www.csun.edu/cod/conf2001/proceedings/0120may.html). Currently under development by the Sendero Group and others are "Smart Phones", cellular phones with GPS capabilities.

There are many advances in the range of items available to remove the functional barriers for individuals with visual disabilities. Many major appliance companies, such as Whirlpool and GE, provide Braille panels or instructional manuals for their equipment. Medical measurements of blood pressure, glucose or weight can also be announced verbally or with tactile symbols. Talking watches, clocks, calculators, food scales, and other appliances minimize the obstacles to activities of daily living. Braille 'n Speak is an example of an auditory organizer, calendar, note taker and talking clock all in one (Blazie Engineering).

Assistive Technology for Communication

Communication disabilities limit an individual's ability to exchange information, ideas, or feelings with others. They may involve problems with hearing, articulation, voice fluency or language. Speech disabilities involve difficulty producing the actual sounds of language. The causes of speech and language disabilities are varied and may include brain injury, malfunction of the respiratory or speech mechanisms, organic causes (cleft palate or cerebral palsy), or disorders resulting from stroke or other unknown causes (Owens, 1999; Smith, 2001). The National Information Center for

Children and Youth with Disabilities (2002, ¶ 2) estimates that "communication disorders (including speech, language, and hearing disorders) affect one of every 10 people in the United States".

Augmentative and alternative communication devices provide alternative means for individuals with speech and language disabilities to communicate. The type of technology used depends on an individual's communication needs, abilities, and mobility. Augmentative communication aids, such as amplifiers and speech clarifiers, are designed to facilitate the use of speech. Alternative communication devices replace speech and range from low tech (picture boards) to high tech solutions (dedicated voice output devices). Often these devices are customized and changed for each person as they develop more language and communication skills. For beginning communication needs, touch-pad devices that digitize brief spoken messages can be used. These devices are sometimes easier to use and provide instant access to messages with the press of a button.   The Big Mack Voice Output Communication Aid (Innocomp) uses one large button to access a message up to 20 seconds in length. The Intro Talker (Prentke Romich) is a touch-sensitive board with 8 to 32 squares labeled with pictures or words and is programmable with digitized speech. The Touch Talker (http://www.prentrom.com/index.html) allows the user to create words by combining specific keys in sequence and requires more refined motor skills to access than the Intro Talker.

For more advanced communication, stand-alone electronic communication boards and computers with speech production capabilities facilitate communication for users without speech. Communication boards use either synthesized or digitized speech and may be activated by touch or connected to switches. The Liberator (Prentke Romich) uses icons rather than letters to allow the user to express ideas quickly and access messages in memory.   It can be adapted for use with head pointers and other devices and can generate small printouts of messages.
For complex communication, the DigiVox (Sentient Systems Technology) and DynaVox (www.Dynavoxsys.com/) allow for a custom keyboard layout with multiple message levels.

> "My DynaVox has given me the thrill of teaching art classes, being a motivational speaker and living independently," said Rick

Hohn, a writer, artist and ordained minister who lives in Vista, California. Born with cerebral palsy, Rick has given presentations and speeches to numerous groups. "Like most people with severe communication disorders, I hated going to the doctor. I'd come home a basket case after listening to a doctor yell at me as if I was deaf or had no intelligence… Despite that, doctor visits have been more pleasant for me in recent years. It really helps to have my DynaVox with me. I get a charge out of actually educating a doctor, especially if it is my first visit. It is a joy to build a relationship with a medical professional who treats me with dignity and respect" (DynaVox Voices, 2001, p.4)

Assistive Technology for Physical Disabilities

Individuals with physical disabilities are an extremely heterogeneous population. It is estimated that approximately 11 million adults between the ages of 16 and 64 are living with physical limitations (U.S. Census Bureau, 2000). In one survey of 981 individuals with physical disabilities, self-reports of concurrent disabilities included 37% with visual problems, 35% with speech problems, 21% with hearing problems, 31% with cognitive disabilities, 31% with health problems, and 13% with emotional problems (Parette & VanBiervliet, 1990). In the same survey, it was reported that technology was used in all areas of life function, with the most common usage being mobility (57%), self-help (37%), building accessibility (25%), and taking care of the home (24%).

Mobility
Mobility devices such as braces, artificial limbs, canes, walkers and wheelchairs are the most commonly used types of assistive technology. "Mobility and anatomical assistive technologies have different customer bases" (Endlich, 1998). Approximately 5 million seniors use crutches, canes, or walkers; whereas the majority of individuals using braces and artificial limbs are aged 44 and younger.

In 1999, two million adults used a wheelchair, and seven million used a cane, crutches, or a walker (CDC, 1999). Many of these people use more than one mobility device depending on the circumstances. For individuals who are able to bear weight, canes are one of the most commonly used

assistive devices, accounting for nearly two-thirds of all mobility devices (LaPlante, Hendershot, & Moss, 1992). Second to canes are walkers, with over 1.6 million users in the US.

Wheelchair designs (manual, power, reclining, climbing, all-terrain) have benefited from recent technological innovations, such as lighter manual wheelchairs and adjustable power wheelchairs. Still, wheelchair designers need to address multiple issues including repetitive motion injury, safety, affordability, ease of maintenance, and fitting. Adjustable wheelchairs, although very expensive, allow the user to automatically lift to a vertical position (Tumble Forms Stander, made by Sammons Preston). A less expensive alternative for assistance in standing is a standing table (Lifestand, made by Independence Providers, Inc.) Electric powered scooters are another power mobility alternative for individuals who can sit upright. These also seem to be popular among older people who see a scooter as liberating and less stigmatizing than a traditional wheelchair.

Prosthetic and orthotic devices improve function for amputees and users needing support in movement. Products range from devices to replace upper and lower extremity functional limitation or loss to appliances to provide support and movement of the joints, torso and pelvic area.
A research priority of NIDRR is the development and evaluation of prosthetic and orthotic devices. For individuals with amputations fitted with prostheses there is an unusually high rejection rate. The Los Amigos Research and Education Institute (LAREI) is developing criteria for optimal orthotic prescriptions in patients in an effort to reduce abandonment.

Other means of enhancing mobility include removing barriers to accessing public transportation and modifying privately owned vehicles. Many adults with physical disabilities use adapted driving controls to make personal vehicles accessible, enabling considerable independence, particularly in rural areas. Public transportation can be made accessible through the use of lifts, ramps, adapted seats, straps, cushions, and transfer aids, including wheelchair and scooter securement systems and airplane transfer chairs.

Environmental Control Aids
Environmental control units (ECUs) allow individuals with physical disabilities to independently complete a variety of daily living tasks, from opening doors and operating TVs, to using the telephone and accessing

online services (Scheiderman, 1994). The technology ranges from low tech single switch devices (PowerLink2) to high tech computer options for operating multiple devices simultaneously (Stefanelli, 1994).
Some devices (i.e., prone cart) have been updated to take advantage of new materials and design research. Others are merely adaptations of common objects to make them more utilitarian, for example, a television remote control device (RERC-Aging) with large buttons and high color contrast to help persons with disabilities control environmental settings. Consumer electronic stores and major hardware franchises often carry easy to install devices for controlling lights, TV or other electric appliances through a remote or signaling device. The costs of these mass marketed devices are often far lower than specially designed "medical" equipment.

Radio-activated and voice-activated (Mastervoice) control units are two high tech assistive devices used to activate numerous appliances, including phones, alarms, appliances, and timers (Stefanelli, 1994). Personal computers serve as control units that allow users to manage various functions in the environment. Another recent innovation in accessibility is robotics, "ranging from sensory feedback with a virtual headstick to a gesture-programmed, multimodal robot" (Fiedler, 1996). The Robotic Work Station Attendant is an ECU that uses a robotic arm controlled by a computer to turn pages and operate office equipment. The unit can be operated with voice input, keyboards, or row scanning. The X-10 Controller unit is another device that allows the user to operate lights and appliances with either a remote control or personal computer.   One study of X-10 with nursing home patients found that those who had X-10 used their radios and lights significantly more than a control group (Mann, 2001).

Andrew Lyon, a rehabilitation technologist at Shepherd Center in Atlanta, describes how individuals at the Center control lights, TVs, and telephones using a sip-and-puff system. "Sip-and-puff is a pneumatic switch. You suck or blow into it and it makes contact to call the nurse. It's like pushing a button…We also put an adaptation on their TVs so that with a puff they can turn it on and change the channels, and with a sip they can turn it off. We've adapted a speakerphone so they can sip to turn it on or answer it, and when they're finished talking they can sip to turn it off." Another adaptive telephone device is the Vocal Link Cellular Module, which is a voice recognition device that connects to a standard cellular telephone and allows users to call pre-stored numbers using voice commands.

Manipulation / Agility

Agility aids assist individuals with limited or no use of their hands in completing activities of daily living. Low-tech devices for opening food jars or medication bottles, grasping containers, or turning doors can restore functional independence. Similarly, the wide variety of special plates, utensils, and cups remove some of the barriers of eating and clean up for a person who has limited use of their hands and arms. For individuals with more severe physical disabilities, the Winsford Feeder (North Coast Medical, Inc.) is an automated feeding machine that can be operated with a hand, shoulder, knee or hip. There are also a wide array of devices for dressing and a variety of clothing options. Adapted clothing may eliminate the obstacle of traditional fasteners and ease the task of dressing. Independence in personal hygiene is supported through the use of raised toilet seats, grab bars, commodes, or lifts that eliminate or limit the need for a caregiver (Mann, 2001).

For individuals with deficits in hand strength and dexterity, splints and adaptive aids allow for increased function. Individuals with arthritis or cumulative trauma disorders may use AT to improve coordination, manipulation and reduce pain. Shoes aids allow people who have back pain to pull on shoes without bending. Adapted switches help with turning on and off appliances. Writing devices assist those with limited grip and key holders provide for better grip and leverage when using a key. An increasingly common issue affecting manipulation ability stems from repetitive motion injuries, such as Carpal tunnel syndrome. In spite of the fact that many ergonomic devices have been developed to address the problem, the incidence of this condition continues to increase. A study by Li, Liu, Miyazaki & Warren (1999) found that splinting led to a decrease of symptoms and an improvement in functional status for individuals with carpal tunnel syndrome. A recent innovation, The Freehand System (http://remoteability.com/unique/freehand.htm), is a functional electrical stimulation system that involves a surgeon attaching electrodes to muscles in the hands and forearms. In clinical trials, individuals using the Freehand System demonstrated improvement in pinch force, hand function, and level of independence in activities of daily living (Davis, Mulcahey, & Betz, 1999).

Interface Devices

One of the most significant advances to telecommunication and information dissemination has been the Internet and World Wide Web (Lindsey, 2000). However, access to information technology, including the Internet, for individuals with disabilities often requires an alternative means of operating devices, from alternative mouse and keyboards to remote control devices (Lyon, 1999). For many individuals with movement disabilities, controlling a computer mouse or cursor is difficult. Some of the simplest solutions are options or accessibility features built into many operating platforms, including screen magnification and the ability to adjust the speed of the mouse or key repeat rate. Another example of universal design in current operating systems is electronic key latching (sticky keys) that enables a user to perform simultaneous key presses and may be useful for someone typing with one hand or using a mouth stick to operate the keyboard. Other writing or typing aids include keyguards, screen guards, and word prediction software. CFILC plans to focus a research project on the Internet and computer use among people with disabilities later in the grant timetable.

Alternative keyboards provide another option for individuals who have physical disabilities. Discover Board (www.donjohnston.com) is an oversized keyboard whose appearance and sound can be modified using overlays. IntelliKeys (http://www.intellitools.com) are overlays that allow standard keyboards to be customized. For individuals using a hunt-and-peck system of typing, the Half-QWERTY Keyboard (Matias Corporation) reconfigures the keyboard to make the most commonly used letters more accessible. A mini-keyboard (TASH International) might also be used if muscle movements are restricted and /or if the keyboard needs to be attached to a wheelchair. Another option for limited hand dexterity is a chording keyboard (BAT Personal Keyboard, made by Infogrip, Inc.) that activates the computer using combinations of only seven keys. Touch control devices can also be used in lieu of a mouse or standard keyboard. Touch window (www.learningneeds.com) and Gemini (http://www.assistivetech.com) both allow for computer control by touching the monitor surface. Gemini can also be operated using a joystick or headmouse.

Wands, mouthsticks, and headsticks are among the many devices that target a user's available motor skills. For example, the "Tonguepoint" system (IBM Trackpoint III Trademark) is comprised of a pressure-sensitive

joystick fastened to a mouthpiece that can be operated by the user's tongue. The joystick provides cursor-control, while two switches, a bite switch and a manual switch, allow the user to use the left/right click buttons. The Headmouse Trademark (Origin Instruments) uses a wireless optical scanner to turn head movement into cursor control. Mouse functions are controlled by dwelling over a key for a set period of time (Barreto, Scargle, & Adjouadi, 2000). Other "hands-free" alternatives for controlling input are voice-activated systems with speech recognition capabilities. WordWave (http://www.wordwave.com) is a speech-dictation product that enables voice-activated Internet searching using standard search engines.

A more complex method to computer interface is the eye-gaze tracking interface approach. In conjunction with an onscreen keyboard, this system enables a user to fully operate the computer without using any extremities. Although the user is able to quickly move the cursor across the screen, the execution of fine, small cursor movements is not easy and requires strenuous control abilities. Furthermore, if the user changes position or moves enough to shift his/her eye out of the field of vision of the camera, the operation is disrupted. At present, some eye-gaze systems do attempt to compensate for the movement of the subject by using a pan-tilt camera and adding a magnetic head tracking device. Results are improved with this addition, but unfortunately at the expense of added complexity and cost.

Another approach is the Brain-Computer Interface (BCI) that uses electroencephalographic (EEG) waves originating in the brain. One of the major limitations of BCI systems is the high potential for electromyographic (EMG) contamination. Any muscle movement on the head or neck can produce "noise" contamination from the corresponding EMG signal. From an application standpoint, this is a big inconvenience to a user, especially if the user has movement-related disorder such as cerebral palsy.

The EMG/EEG-based Human-Computer Interaction system is an alternative to eye tracking systems and when combined with an on-screen keyboard is fully operational without using any extremities. The system transforms biosignals into controls for two-dimensional cursor movement. In contrast to eye tracking systems, the HCI system has the potential to be relatively inexpensive and portable and eliminates some of the concerns related to eye tracking systems, such as "dwell time", user training, and loss of calibration (Barreto, Scargle, & Adjouadi, 2000).

Sip and puff-activated systems (e.g., Head Master Plus), like the one used by Greg Smith, lead software developer at Microsoft, allow users to operate a computer without a keyboard or mouse. "As a result of a football injury that left him without the use of his legs and with very limited arm movement, Smith uses a head pointer and a sip-and-puff device in lieu of a mouse to maneuver the desktop. Keyboarding is done with a pointer attached to his right arm." (Mottl, 2001).

Another access method for individuals with motor impairments is the use of switches. A switch can be used to operate a wheelchair, dial a telephone, control a computer, or complete any number of other activities. Switches are available that match almost any users motor control (http://www.dynavoxsys.com/). For example, a Jelly Bean Switch (www.ablenetinc.com) can be operated by moving any part of the body through an infrared beam. The selection of an appropriate switch requires an assessment of the environment and context in which it will be used, and the motor characteristics of the user. Depending on the switch placement and use, there may be a need for a variety of switches. For example, Sam spends six hours a day in his wheelchair. "During this time he is competent in using a wobble switch positioned at the right side of his head and mounted to his wheelchair. From there he operates an auditory scanning augmentative communication device. However, when he lies in a reclined position in bed, his head rests on the pillow and he cannot operate the wobble switch reliably. When in bed, Sam uses a pillow switch pinned to the pillow next to the right side of his head. From this position, Sam turns his head to the right to activate the same augmentative communication devices" (Angelo, 2000). Switches may also be used in conjunction with control enhancers, such as splints and forearm supports to increase the accuracy and efficiency of switch use.

Assistive Technology for Cognition

Technology for enhancing cognitive function focuses on assisting individuals with performing activities of daily living. Technology is also increasingly playing a role in the lives of seniors as they acquire disabilities due to age or other factors. "Of all impairment groups, elders with cognitive disabilities used the fewest number of assistive devices" (Mann, 1995). Individuals with cognitive disabilities have less access to technology than others with disabilities (ATA, 1999). There is a tendency to focus on the use of assistive

technology for safety when working with individuals with cognitive disabilities; however the individual may be more concerned with enhancing quality of life (Marshall, 1999).

Cognitive disabilities include limitations in memory, concentration, and processing to difficulties in decision-making and communication. Disabilities may be congenital, environmental or due to traumatic brain injury, dementia, stroke, Alzheimer's, or other progressive diseases. Problems encountered in everyday life may include understanding instructions, reading, using the phone, accessing public services, conducting activities of daily living, following routines, managing interpersonal relationships and understanding safety hazards. A significant barrier for individuals with cognitive disabilities, and those without, is the complexity of the technology and the demands placed upon the user.   Therefore, individuals with cognitive disabilities may need more support and instruction to be successful users of AT.

Accessibility is a major concern when identifying technology for individuals with limitations in cognitive functioning. From heat sensors on stoves to electronic sensors on doors, the availability of technology to assist individuals functioning in their own homes is increasing. However, for individuals with dementia, AT is often one component of a comprehensive approach that may also include trained staff, response centers, and adaptations to the house itself.

> Mr. Frank has dementia and wears a signaling device to alert caregivers when he attempts to leave the house. Since he can no longer remember telephone numbers, he has a telephone reminder pad with photographs of people he can press to dial their number. Mr. Frank often forgets and leaves pans on the stove. The stove is designed to register when the pan is empty and automatically turn off. However, as a back-up security precaution, the smoke detectors and heat sensors in his home are linked by computer cable and when activated automatically alert a local resource center. In addition, the computerized system in the house switches on a fan, turns off the stove, and unlocks the front door (Marshall, 1999).

"Smart houses" (Clatworthy and Bjorneby, 1997) in which items of household equipment are linked to each other and to a personal computer,

as illustrated by the case of Mr. Frank, are rare, however approximately 14 million Americans with disabilities live in homes modified in some way to meet their needs (Carlson, Ehrlich, Berland, & Bailey, 2001). "In addition to customization of environmental controls, such as heating and lighting, facilitating communication is another application of smart technology. As opposed to helping individuals adapt to technology, smart technology is that which adapts to the needs and preferences of users" (Fozard, Rietsema, Bouma, & Graafmans, 2000).

Another cognitive aid that works in conjunction with a support center is "Isaac". Developed through a collaborative effort in Sweden, Isaac is a personal digital assistant consisting of an individually programmed computer and a built-in digital camera as well as a GPS satellite navigation receiver and a cellular phone for conversations and computer communications. The handheld computer's touch screen has simple pictures and symbols. A phone call can be made with Isaac by just touching a face on the screen. The GPS receiver helps a person find out where he or she is and the digital camera serves to document the day and to photograph places and things the user is unsure of. A key component of this system is the support center, staffed by trained personnel available to answer questions, provide directions, and offer immediate assistance if needed (Jönsson, 1994).

Other assistive technology devices include trackers and wandering aids, reading aids, conversation or writing aids, and emergency/call systems. Portable devices for memory and organization (http://www.biausa.org) are available for individuals who need to be cued. A computerized paging device can be used to alert the user when it is time to take medication or as an appointment reminder. Emergency systems are also available and can alert the wearer to raised body temperature or heart rate. Often individuals with brain injury and mental retardation experience social isolation. Think and Link is a project designed to increase the access to and use of electronic mail by individuals with cognitive disabilities (http://www.think-and-link.org/).

Universal Design

Universal design incorporates features that make products or places universally accessible for users with a wide range of abilities. The Center for Universal Design (1997), at NC State University, established the following seven Principles of Universal Design to evaluate, guide, and educate

designers and consumers: equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, and appropriate size and space for use. Examples of universal design include sidewalk curb cuts, electric doors that operate using sensors, height-adjustable tables, walk-in bathtubs, and design changes to personal computers (power switches moved to the front of the computer). Incorporating principles of universal design into the environment reduces the need for "orphan technology" that is user specific and expensive. "Making standard technology usable by more people with disabilities raises awareness, reduces cost, improves options and availability, and reduces the reluctance of some toward the use of technology" (Alliance for Technology Access, 1999). Despite its appeal, the implementation of universal design is hampered by cost and the lack of regulatory agencies requiring UD in consumer products (Bowe, 1995).

Impact on Users

In a survey conducted by the National Council on Disability, adults of all ages were asked to assess the impact of AT on their lives. They rated the impact on a scale from 1 to 10, with 10 being high. When asked to rate the quality of their life without AT, the mean was 3.0. But, when rating quality of life with AT, the rating soared to 8.4 (National Council on Disability, 1993). However, the impact of AT depends, in large part, on the appropriateness of the AT device and the user's overall success with the equipment. Since appropriateness is extremely individualistic, assessment is a key component. Factors to consider when determining the appropriateness of technology include, affordability, availability, compatibility, portability, usability and trainability (Lueck, Dote-Kwan, Senge, & Clarke, 2001). Will the technology allow a user to perform desired functional tasks? Will the device be compatible with the user's social, emotional, and skill level? Will it be compatible with existing technology? Assistive technology "can permit individuals to be environmentally, vocationally, and emotionally empowered" (Fiedler, 1996). In addition to matching users with appropriate tools, the type and degree of disability influence the impact of AT on a user. Using the Psychosocial Impact of Assistive Devices Scale (PIADS), users were asked to rate the impact of wheelchairs within the first three months of use. Individuals with degenerative diseases report less favorable impact than users with spinal cord or brain injuries (Jutai, 2001). Other research using PIADS supports that the perceived psychosocial impact of AT for activities of

daily living changes over time and varies based on type of device and disability, but that the psychosocial impact is often positive and prospective AT users have realistic expectations (Jutai, Rigby, Ryan & Stickel, 2001).

Impact on Families / Caregivers

"Assistive technology devices can have a dramatic impact on family routines and relationships in both positive and negative ways" (Parette & Angelo, 1996). AT may increase the independence and functioning of an individual with disabilities, while at the same time initially increasing the demands of family members and caregivers.   Caregivers may be responsible for ensuring the function and efficiency of the new assistive technology (Zagler & Panek, 1999) and may need to take on new roles as teachers or trainers. A great deal of research pertaining to family and caregivers of AT users is focused on children and their parents.

> "Although assistive technologies may relieve families of some worries about the recipient child and of burdens in the child's care, they also may generate unique stresses of their own. Assistive technology devices may require additions to family routines (e.g., daily battery charging or cleaning), restrictions of family activities (e.g., hindrance on travel due to size/portability problems of an electric wheelchair), and/or modifications to the home environment (e.g., setting aside "protected" space for a video enlarger system…Technology demands placed on primary caregivers may contribute to a reduction of energy available for other important family functions)" (Parette & Brotherson, 1996).

Mann (2001) examined the potential of assistive technology to ease the burden of caregivers and concludes, that "Any device that increases the level of independence for a person will at the same time decrease the amount of assistance required from a care provider" (Mann, 2001). Studies have demonstrated that there is an increase in independence and decrease in cost associated with the use of AT (Mann et al., 1990, Cummings et al., 1990). Both high tech (mechanical ventilation devices) and low-tech (grab bars) devices have been demonstrated to relieve use of care providers (Mann, 2001). Associated with this is the level of expertise and motivation of caregivers responsible for the implementation and function of an assistive device (Zagler & Panek, 1999). Another interrelated factor is the influence of

culture on individuals with disabilities and their caregivers. How family members, caregivers, and/or communities view disability, the role each plays in the life of a person with a disability and the attitudes toward technology all influence the impact of AT.

Barriers Inhibiting Access to AT

Information/Marketing
How do individuals become informed consumers of assistive technology given that, "There is no Consumer Reports for assistive devices?" (Bryant, 1994). Although there is no single source of information individuals can rely upon, there are information clearinghouses, computer programs, and consumer-oriented bulletin boards that do provide some of the information needed to make an informed choice (Bryant, 1994). One resource available to assist individuals preparing to purchase an assistive device is ABLEDATA. Funded by NIDRR, this database contains information on a wide range of more than 19,000 products and can be accessed on-line (http://www.abledata.com/text2/search.htm), by phone (1-800-227-0216), or using a CD-ROM (CO-NET). This program provides information about specific devices and provides pictures and sound samples. If the user does not know the particular name or vendor of a device, the Adaptive Device Locator System (Academic Software) searches according to functions that individuals need to perform. Other options include the National Rehabilitation Information Center, Project LINK (1-800-628-2281), assistivetech.net (http://www.assistivetech.net/), or an Alliance for Technology Access Center.

Who accesses these services? Alliance for Technology Access (ATA) is a network of resource centers, vendors, and developers dedicated to connecting individuals with disabilities to technology tools. ATA (1999) reports that African Americans with disabilities in their study, by and large, learned about new assistive technology through the mainstream media and family and friends. Many minority and/ or low -income individuals lack connections with the "disability community" and therefore lack current and adequate information on the wide array of AT devices available. Of California's 6.6 million people with disabilities, a disproportionate number are low-income minorities. Native Americans have the highest rates of disability, with Caucasian, African American, and Hispanic rates in the intermediate range. Disability rates are lowest among Asian-Americans (McNeil, 1997),

however factors such as age, family structure and income level obscure interactions with race and ethnicity (Fujiura, Yamaki, & Czechowicz, 1998).

Retention / Abandonment of AT

Many psychosocial factors impact the use or non-use of AT, including personality, response to disability and the environment or social milieu in which technology is used (Krefting & Krefting, 1991).   Several factors have been identified as contributing to AT abandonment, including lengthy wait times (Bhatt, Kohli, Melvin, & Maiman, 1987), improved physical function, replacement by alternative devices (Garber & Gregorio, 1990), and level of training and misalignment with individuals goals (Beigel, 2000). The latter, failing to take into consideration a user's ideas and desires for the device, is a primary reason for abandonment (Scherer, 1993). Some expensive devices (orthoses) are retained more often, perhaps due to the research and time involved in selecting and fitting the devices (Fiedler, 1996). Products that are universally designed are also more attractive and may decrease abandonment, as they are free from the stigma often associated with disability (Fozard, Rietsema, Bouma, & Graafmans, 2000). Users should be involved in all phases, from needs assessment through procuring the device. Discussions about needs and technology preferences should include factors such as personality and prognosis of user, type of disability, availability of device, financial resources, training and support, and physical, sensory and cognitive factors.

Some of the questions that still need to be researched include:

1. How can ILC and Community Based Rehabilitation services increase the use of AT among consumers with disabilities?
2. How can AT be marketed to improve consumer knowledge of its availability?
3. How can AT be marketed to reach rural, low income, non-native English speaking and minority consumers and their caregivers?
4. What, if any, action should be taken to change cultural or familial attitudes toward assistive technology?
5. What training and financial resources are needed to increase the use of technology by individuals from culturally diverse, rural, and low-income communities?
6. Are culturally sensitive training materials for assistive technology being used?

7. How can information, referrals, and resources be coordinated across the numerous service providers of AT?
8. How can information, referrals, and resources be provided to people living in rural areas?

Research on the above questions should be carried out rigorously and with significant input from, and direction by, people with disabilities. NIDRR supports the use of participatory action research and use of the new paradigm of disability that integrates the individual and the environment to produce 'disability'. If you have comments, suggestions, additions or ideas for important research topics please contact the CFILC Community Research for Assistive Technology project.
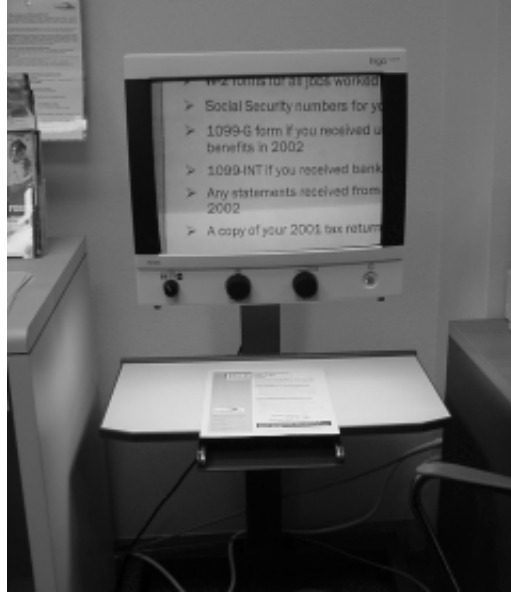
SUCCESS STORY

Assistive Technology & Funding

PeninsulaWorks Redwood City

Oftentimes when you hear a success story, the story revolves around an individual's personal accomplishments. There are many times where businesses, agencies and organizations have been successful as well. We just don't hear about them very often. When looking for a success story regarding funding assistive technology, CR4AT wanted to highlight an organization that had been successful in removing barriers to access for its clients by getting AT funded and installed in their business.

PeninsulaWorks Redwood City, a One-Stop Employment Center, is our funding success story. By law, they are required to have an accessible location to serve their clients looking for employment. They have taken further steps to ensure that they are inclusive in their accessibility for all the types of people who walk through their doors. The PeninsulaWorks Redwood City One-Stop Employment Center purchased assistive technology to provide information access for people with disabilities who are conducting job searches.

Equipment purchased included literacy software for people with reading challenges and learning disabilities (WYNN Wizard and textHELP! Read & Write). Screen Reading & Magnification software (ZoomText), a Large Print Keyboard, an ERGO CCTV (Video Magnifier) for the visually impaired, a Trackball Mouse and an Adjustable Height Workstation for people with physical disabilities.

Funding for the equipment was provided through a grant administered by the California Department of Rehabilitation and EDD. We purchased the equipment from a local AT vendor, Access Ingenuity, in Santa Rosa, CA (877-579-4380) - they also provided staff training on the use of our equipment.

The equipment was just installed at the end of October 2002 and customers are just becoming aware of the equipment. We are developing plans to educate clients and other referral agencies about our new services.

PeninsulaWorks is looking at the development of access solutions for our clients with disabilities as a long term process - one that involves both building internal staff awareness and communication skills to work with clients as well as providing access solutions (i.e. assistive technology). This approach allows us to start providing services now - and modify or enhance our services as our client needs change.

CHAPTER 6

Funding for Assistive Technology in California: What we know now

By Liz Arjun, M.P.H., M.S.W. and Tanis Doe Ph.D.

Introduction

As a result of our initial contacts, additional topics relevant to the use of Assistive Technology began to emerge. Difficulty in accessing the necessary funding seemed to be a common issue across all four research areas. Consumers with disabilities suggested that we disseminate what was already known about funding and work on changing existing barriers to obtaining funding. This paper is a response to that need. It will provide some clarity about the different funding streams within California and outline the difficulties that people with disabilities have when attempting to locate funding for assistive technology.   We are seeking feedback on this paper and will integrate key questions about funding into the next stages of research including focus group and survey methods in the coming years.

Background

There is little data available regarding the use, need, and satisfaction of AT users. The scant information that does exist is generally derived using data from the National Health Interview Survey. One study conducted in 1992 (LaPlante, Hendershot, & Moss) found that 13.1 million persons used AT, an additional 2.5 million persons needed AT, and that of this 2.5 million, 60% could not pay for the needed AT.

Carlson, Ehrlich, Berland, & Bailey (2002) conducted a national survey regarding the use, need, and satisfaction of AT. This study was a joint effort by the NIDRR, the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), and the University of Michigan. This study found that 64% of people with disabilities used some type of AT usage was 36% at school and or at work, 49% at home, and 50% in the community. Regarding the funding of AT, it was found that more than a third paid for AT themselves and another third received funds by public or private insurance. Finally, it was reported that only 20% of AT users received help in the selection and purchase of their AT and that of this number, 50% received the advice from their medical providers.

In 1993, The National Council on Disability (NCD) conducted a project entitled, "Study of the Financing of Assistive Technology Devices and Services to Individuals with Disabilities". This study was funded under the original 1988 Tech Act to provide recommendations to the President and to Congress on improving access to the financing of assistive technology. Many of the findings from this study in 1993 were echoed in the initial stages of the Community Research for Assistive Technology (CR4AT) project. "Current, reliable, and easy-to-understand information remains out of reach for many persons with disabilities and their family members" (National Council on Disabilities, 1993, p. 15). Significant recommendations emerged from the NCD research study in response to these findings and were made to the President and Congress.

A) "Establish the statutory authority for a federal Assistive Technology Interagency Coordination council to meet quarterly and be responsible for improved coordination of services and funding for assistive technology for Americans with disabilities" (National Council on Disability, 1993).

In many states, the government provides funding to various entities to address issues of system change to promote interagency coordination around assistive technology. The Assistive Technology Network at the California Foundation for Independent Living Centers (CFILC) has an ongoing change component built in for interagency coordination. We are providing a network that allows for more information to be disseminated regarding AT. However CFILC do not yet have collaboration with the funding agencies, including educational, vocational, and medical service providers.

B) "Amend the individual program planning requirements in multiple statutes to provide notice to individuals with disabilities and their families of the right to assistive technology devices and services in response to individualized needs in a timely manner" (National Council on Disability, 1993).

The Department of Rehabilitation and Special Education programs have addressed this recommendation by including phrasing that AT must be considered for Individual Education Programs in Special Education as well as in the Individual Plan for Employment (IPE) through the Department of Rehabilitation. The implication of this recommendation is that it promotes the use of AT in educational and vocational settings. It also promotes the consumer to be aware that such technologies are available to them in their goal setting.

C) "Reauthorize the Tech Act for an additional three years and strengthen opportunities for interagency coordination, systems change, and consumer choice and control" (National Council on Disability, 1993).

In 1998, the Assistive Technology Act was signed with the intention of increasing interagency coordination, systems change, and consumer choice and control. The passage of the Assistive Technology Act of 1998 P.L. 105-394 implemented a variety of programs and policies affecting the availability of assistive technology. Funding was made available for a variety of specific tasks at the state level to do the following:
- Support a public awareness program that is designed to provide information related to the availability and benefits of assistive technology devices and services that are linked to a proposed national public internet site (RESNA, 2002).
- Promote interagency coordination that improves access to assistive technology devices and services for individuals of all ages who have disabilities (RESNA, 2002).
- Provide technical assistance and training including the development and implementation of laws, regulations, policies, practices, procedures, or organizational structures that promote access to assistive technology devices and services (RESNA, 2002).
- Provide outreach support to statewide community-based organizations that provide assistive technology devices and services to individuals with disabilities or that assist individuals in using assistive technology,

including focusing on individuals from underrepresented and rural populations (RESNA, 2002).

The purposes of this NCD recommendation and implementation were threefold: (a) to support states in their capacity to address the assistive technology needs of individuals with disabilities; (b) to support the investment in technology across federal agencies and departments that could benefit individuals with disabilities; (c) to sponsor micro-loan programs to individuals wishing to purchase assistive technology devices or services (RESNA, 2002). It is clear that the overall goals of this policy were to lessen barriers to obtaining assistive technology due to the lack of coordination between agencies as well as financial constraints posed to consumers by the high cost of many assistive technology devices. Unfortunately, at this time, barriers due to the lack of coordination among the different funding agencies still exist.

D) *"Establish Assistive Technology Demonstration and Recycling Centers nationwide in an appropriate city of each state… to be operated by existing Centers for Independent Living or other community-based organizations that are consumer controlled and directed to enhance consumer choice and control of assistive technology services and funding (NCD, 1993).*

Most users of assistive technology are unable to test the technology or device prior to its purchase. Unfortunately, this often results in the purchase of AT that is not appropriate, which leads to abandonment of the device. By providing demonstration and recycling centers, consumers have the opportunity to tryout or "test-drive" their future purchase to decide if it actually meets their individual needs and lessen retention issues (National Council on Disability, 1993).

Currently there are several Demonstration and Recycling centers in the state of California. However, these centers are located haphazardly and serve only the immediate areas in which they are located. Centers that are more geographically central and target more than one population may better serve a wider range of consumers throughout the state.

E) *"Authorize by statute the establishment of a National Center on Assistive Technology Legal Advocacy to specialize in funding issues"* (National Council on Disability, 1993).

The reauthorization of the Tech Act in 1998 authorized funding for state protection and advocacy systems to assist individuals with disabilities in acquiring assistive technology devices and services. This funding came jointly from the U.S. Department of Education and the National Institute on Disability and Rehabilitation Research (NIDRR) to the entity in each state to support protection and advocacy services through the Developmental Disabilities Assistance and Bill of Rights Act (RESNA, 2002) for a six-year period. In the state of California, this organization is Protection and Advocacy, Inc. (PAI). Up until March 2002 PAI had been receiving monies to provide training and a resource manual entitled, <u>Accessing Assistive Technology</u>, outlining the various funding streams in California. Currently, they receive a small amount of money each year to provide legal assistance regarding issues consumers may have in obtaining AT. The work of PAI has resulted in dissemination of information regarding funding decisions and the provision of technical assistance to groups and individuals regarding their right to assistive technology.

F) "Create a comprehensive set of fiscal incentives encouraging private industry to invest in the production, marketing, and distribution of assistive technology to benefit Americans with disabilities" (National Council on Disability, 1993).

One example of a fiscal incentive is Section 508 of the Rehabilitation Act which requires that when federal departments or agencies develop, procure, maintain, or use electronic and information technology, such as web sites, that individuals with disabilities have comparable access to it. Additionally, the Tech Act of 1998 requires that all states that receive federal funding be in compliance with Section 508 (National Council on Disability, 2000). The purpose of these policies is to increase the contribution of the federal government in promoting the development of assistive technology that is readily available and accessible to people with disabilities.

G) Amend Section 162 of the Internal Revenue Code to allow taxpayers with disabilities who do not itemize the option of claiming assistive technology expenses as above-the-line adjustments to income. Request that the Department of Treasury develop a cohesive set of tax policies on assistive technology for persons with disabilities that clarifies national values and goals as articulated in the ADA and the Tech Act.

There are a variety of tax incentives to assist persons with disabilities in the purchase of AT. For example, many AT items such as home and vehicle modifications are deductible on personal income taxes as medical expenses. However the option to claim assistive technology as a deduction to income that is taken before calculating the tax remains an option to leaving it as a regular medical expense.

H) "Authorize by statute universal product design guidelines for application in the manufacture of electronic equipment and other products to enhance accessibility by individuals with disabilities" (National Council on Disability, 1993).

The Television Decoder Circuitry Act of 1990 (Arizona Technology Access Program, 2002) that employed the use of universal design as a means by which to provide assistive technology has met part of this recommendation. This Act required that all televisions with a 13 inch or larger screen manufactured in the United States be built with close-captioning decoder chips (Mendelsohn, 1997).   In addition, the passage of the 1996 Telecommunications Act (Arizona Technology Access Program, 2002) requires that telecommunications equipment and services are accessible where possible, or compatible when not. This is to ensure that manufacturers and service providers consider access to assistive technologies in the design of new products. However, to date, no legal guidelines have been established.

A few NCD recommendations have yet to be acted upon. These are burning issues that, a decade later, still pose barriers for consumers who need funding for AT:

A) "Mandate by statue the development of a national classification system for assistive technology devices and services and establish and collect uniform data sets across public programs" (National Council on Disability, 1993).

The implementation of this recommendation would allow for better tracking regarding the use and success of assistive technologies to better understand the needs of consumers. It would also allow more informed

resource allocation. The implementation of this recommendation is dependent upon a national classification system of assistive technology across the potential funding programs (National Council on Disability, 1993). Currently, each agency has different definitions and classifications of AT.

B) Add the complete definition of assistive technology devices and services adopted in the Tech Act to the following programs of the Social Security Act: Title II, Social Security Disability Insurance; Title V, Maternal and Child Health Block Grant; Title XVI, Supplemental Security Income; Title XVIII, Medicare; and Title XIX, Medicaid.

While many of these agencies have definitions for assistive technology, there is still no uniformity as to what is considered AT and what is considered "medically necessary" or "durable medical equipment". This recommendation is similar in scope to the recommendation regarding a national classification system.

C) Develop statutory authority that requires private health insurance to apply medical necessity standards to durable medical equipment, prostheses, and orthotics that enhance function in activities related to health, safety, and activities of daily living (ADLs).

There has been no progress on this issue; in fact, private health plans operate largely under their own auspices and the provision of much assistive technology is dependent on the individual policy. Private insurance is an important source of funding for assistive technology, yet there are difficulties in accessing it as a source because of variability within plans, limitations of various services and devices, and the use of terms such as "medically necessary". The hope of this recommendation was to promote the use of private insurance as a more reliable and comprehensive funding source for assistive technology beyond the health care setting on a long-term basis. Currently the CFILC is working with representatives of various HMO's regarding comprehensive inclusion of AT coverage in their health plans.

The Current Funding Situation in California

There has been progress on many of these recommendations that were made by the NCD study. However, it is also clear that the progress is not

comprehensive or well coordinated: issues of conflicts between federal and state statutes, interagency coordination, and private and public funding sources create a situation that still make locating the necessary funds for assistive technology difficult. "The two biggest barriers identified by consumers were lack of information and knowledge about appropriate AT and lack of funding to purchase AT" (National Council on Disability, 2000). In the first year of research conducted by CFILC we found similar priorities among consumers and experts. People with disabilities want more information and knowledge about AT and need access to funding to get it. The NCD 2000 information was taken from "Federal Policy Barriers to Assistive Technology," a federal report required as part of the 1998 Assistive Technology Act (National Council on Disability, 2000). This report found that many of the barriers identified in the 1993 study remain barriers today. An overview of the various funding resources in the state of California demonstrates the barriers and funding gaps that exist for consumers trying to obtain AT.

Three basic funding streams are available for assistive technology, medical, educational, and employment-based funding. Within these streams AT can be obtained through a variety of mechanisms. We have chosen to focus on the medical and employment based streams since these two areas are most applicable to the overall goal of the research project in addressing the role of AT in health, employability, function, and independent living.

Medically-Based Sources of Funding for AT

Private Health Plans
What they are and who is eligible:
Private health plans have no (legal) requirement to cover assistive technology; self-insured employers must follow the Employee's Retirement Income Security Act (ERISA), which covers employer-provided health plans, whether an HMO (Health Maintenance Organizations) or conventional insurance plan. Regarding assistive technology, most private health plans do not list specific devices or equipment as plan benefits. Health plans will only buy technology services that are deemed medically necessary, often implying that the requested service or equipment must cure or alleviate a medical condition, reduce pain, or help maintain or obtain more normal function.

The provision of assistive technology using private insurance plans is made available under the "durable medical equipment" category (Mendelsohn, 1997). Assistive technology is customarily considered durable medical equipment, prosthetic devices, or equipment associated with occupational or physical therapy. However, private insurance plans often impose modest dollar coverage on durable medical equipment (DME), rendering this source of funding often unavailable in supporting an individual's ability to function independently (National Council on Disability, 2000). This means that insurance companies may only be willing to fund the AT for DME for the duration of a hospital stay.

What they don't cover/Coordination with Other Agencies:
Many health plans do not cover benefits that are the responsibility of another organization such as Medi-Cal. However, if a person is eligible for Medi-cal, California Children's Services, Regional Centers, or another type of government program, the law requires that the person use the private health plan benefits first. This creates a paradox of who is responsible for payment of devices and services. The main exception to this is that the education system cannot require a person to use their medical plan first (Protection and Advocacy, 2000).

<u>*Medicaid (Medi-Cal)*</u>
Who they are and who is eligible:
Medi-Cal is the State of California's Medicaid program, a federally funded matching program that is administered at the state level. This means that the Medi-Cal program is funded by a combination of federal dollars that are matched to the amount of dollars California is willing to spend on it's state-sponsored health care program. Medi-Cal serves approximately 6 million people in California (Medi-Cal Policy Institute, 2002). Individuals who receive Supplemental Security Income (SSI) or In-Home Support Service (IHSS) are automatically eligible for Medi-Cal and account for approximately 1.5 million of those who receive Medi-Cal (Medi-Cal Policy Institute, 2002). After an individual pays a certain amount each month, Medi-Cal may provide services for a limited amount of time, or may pay part or all of the premiums for Medicare. For a more detailed description of these eligibility requirements, please refer to the <u>Accessing Assistive Technology Handbook</u>, (Protection and Advocacy, 2000).

What Medi-Cal funds:
Because Medi-Cal is a federally funded matching program, it is required by federal law to provide services including emergency room visits, treatment for most chronic illnesses, and home health services to persons aged 21 and over. California has chosen to provide other "medically necessary" services relevant to the provision of assistive technology. Assistive technology can fit under a variety of services including medical supplies, durable medical equipment, or prosthetic devices; however, there are often restrictions placed on services such as physical and occupational therapy.

Medi-Cal's definition of Medically Necessary:
The Medi-Cal definition of *medically necessary* includes those services, medicines, supplies, and devices necessary to protect life, to prevent a significant illness or disability, or to alleviate severe pain (CA Welf. & Inst. Codes §§ 14059.4, 14133.3, as cited in Protection and Advocacy, 2000, p/ 10-17). Medically necessary services include rehabilitation and other services needed to attain or retain the capability for normal activity, independence, or self care. Medi-Cal will not pay for services that it considers "experimental," which might include new therapies for treating autism, for example.

Medi-Cal's definition of Durable Medical Equipment:
 It is defined under Medi-Cal as equipment prescribed by a licensed practitioner to meet the medical equipment needs of the patient and includes such equipment as: canes, crutches, walkers, oxygen therapy equipment, basic and custom wheelchairs, and other devices (Title 22 C.C.R. §§ 511601, 51521, as cited in Protection and Advocacy, 2000, p. 10-21). All items must be medically necessary and Medi-Cal states "Durable medical equipment items are covered only as medically necessary, and only to preserve bodily functions essential to activities of daily living or to prevent significant physical disability" (Medi-Cal Policy Institute, 1992, 82-21). Medi-Cal has argued that a device used for social or educational purposes is not medically necessary. However, this is not in agreement with the California Welf. & Inst. Code § 14059, which emphasizes that the purpose of Medi-Cal services are "for conditions that cause suffering, endanger life, result in illness or infirmity, *interfere with capacity for normal activity, including employment,* or for conditions which may develop into some significant handicap" (Protection and Advocacy, 2000, 10-22). Medi-Cal has provided

funding for a wheelchair or scooter to be used in the home, but has refused to pay for a wheelchair or scooter to enable an individual to get out and participate fully in community life.

Medicare
Who they are and who is eligible:
Medicare is a federally administered health insurance plan for those over the age of 65 and for certain individuals with disabilities who receive Social Security Disability Benefits. Most people who are eligible for Medicare are also eligible for Medi-Cal.   If a person receives both Medicare and Medi-Cal, Medi-Cal is responsible for those expenses that require payment (Protection and Advocacy, 2000).

What Medicare covers:
Medicare's Medical Insurance Part B covers most of what is considered assistive technology, including durable medical equipment, physical, occupational, and speech therapy, and prosthetics. Medicare only pays for services and equipment that are considered *reasonable* and *necessary*. The justification for any item to be paid for by Medicare is dependent on the individual service provider's report. Explanations for durable medical equipment are similar to those outlined by Medi-Cal in that they are to be primarily used for medical purposes, can withstand repeated use, and are necessary to treat an illness or injury, or improve function (Protection and Advocacy, 2000). , It is possible to get a power wheelchair Medicare approved for use outside of the home, but only with great medical justification.

A common occurrence when using funding streams such as Medi-Cal or Medicare is the gulf between need versus want. For example a consumer may have received an electric wheelchair purchased by Medicare. He also wanted a manual wheelchair to aid him in becoming more independent. However, Medicare will only assist in purchasing the electric wheelchair. If the consumer's wants are not compatible with the guidelines Medicare has established he must find other means of obtaining another wheelchair that fits his needs.

Regional Health Centers and AT
Who they are and who is eligible:
Regional centers are nonprofit corporations under contract with the State Department of Developmental Services (DDS) to provide assessment and case management services for people with developmental disabilities. Additionally, regional centers buy necessary equipment and services based on individual needs (Protection and Advocacy, 2000, p.4-1). The Lanterman Act established regional centers and the services they provide. Regional centers serve people who have developmental disabilities, women at high risk of giving birth to a child with a developmental disability, and infants at high risk of acquiring a developmental disability.

Regional centers define *developmental disabilities* as including mental retardation, autism, cerebral palsy, and "other disabling conditions" which are related to mental retardation or require similar treatment to that received by people with mental retardation. The condition must begin before the person is 18 years of age, most likely to continue indefinitely, and constitute a substantial disability. The Lanterman Act defines *high-risk infants* as a child less than 36 months of age whose genetic, medical or environmental history predicts a much greater risk for developmental disability than the general population (Protection and Advocacy, 2000, p.4-1).

What Regional Health Centers fund:
Assistive technology such as *adaptive equipment and supplies and transportation services* is part of the support offered by regional centers that can help in social, personal, physical, or economic habilitation or rehabilitation. The Lanterman Act specifies "wheelchairs, hospital beds, communication devices, and other necessary appliances or supplies" (Protection and Advocacy, 2000, p.4-2). Although there is no comprehensive list of assistive technology, the regional centers are required to provide the necessary assistive technology to help an individual meet the goals of the Lanterman Act. The Lanterman Act includes the equipment, supplies, and transportation services to:

- Alleviate developmental disabilities
- Habilitate or rehabilitate individuals
- Help individuals achieve and maintain independent, productive, and normal lives

This third goal of the Lanterman Act gives Californians offers hope the maintenance of independence is sufficient cause to fund assistive technology to developmentally disabled individuals. Since this goal is already established in legislation expansion in other programs to ensure other disabilities have access to assistive technology across lifespan.

California Children's Services and AT
Who they are and who is eligible:
California Children's Services (CCS) is a statewide program for children under the age of 21 who have a physical disability and meet specified financial requirements. Families who have a gross income of less than $40,000 per year are eligible for medical treatment services through CCS. The Director of the Department of Health Services may authorize treatment services and equipment for children in families with higher income if the cost of care is expected to exceed 20% of the family's adjusted gross income. Children do not have to be a citizen or permanent legal resident of the state of California to receive services; but your child must be a resident at the time. CCS receives its funding from the state and county level. This is common in other states too, but it puts an arbitrary age limit on eligibility. Disability does not end at 21 and many people with developmental disabilities spend a great deal of their adult life learning basic skills not mastered in childhood (Protection and Advocacy, 2000).

What CCS funds:
CCS provides *medically necessary services* and assistive technology related to a child's CCS eligible condition, including durable medical equipment, medical supplies medical appliances, electronic communication devices, and medications.

Medically necessary is defined as "those services, equipment, tests, and drugs which are required to meet the medical needs of the client's CCS-eligible medical condition as prescribed, ordered, or requested by a CCS physician"(22 C.C.R. § 41518, as cited in Protection and Advocacy, 2000, p.5-7). Services include evaluations and purchases of medically necessary assistive technology that includes medical supplies, durable medical equipment (such as wheelchairs), medical appliances (artificial limbs), and electronic or manual communication devices. CCS also provides the

repairs, maintenance, and upkeep on appliances and equipment. Specific examples of the types of medical supplies, durable medical equipment, medical appliances, and electronic or manual communication devices that CCS will fund are given in the Accessing Assistive Technology handbook (Protection and Advocacy, 2000).

CCS and other sources of funding:
CCS only provides amenities that are not the responsibility of a private health plan or Medi-Cal. CCS eligible conditions are serious and severe physically handicapping conditions. Children with mental retardation are not eligible for services based on that diagnosis alone.

Medi-Cal and CCS can be coordinated; a child eligible for both CCS and Medi-Cal is considered "dual-eligible" and in this case should have more access to providers than a child eligible for Medi-Cal alone. However, this process is often haphazard and riddled with obstacles because of unresolved coordination issues between the agencies (Protection and Advocacy, 2000). For these children:

- Medi-Cal pays for the services it covers, but CCS authorizes those services
- CCS provides the Medi-Cal case management; but CCS must pay for the services that it covers that Medi-Cal does not.
- When a child is covered by another health plan, CCS will pay for a child's medical expenses if the health plan will not cover the services or will pay only part of the bill.

Veteran's Affairs (VA) and AT
Who they are and who is eligible:
VA services are for individuals who leave active military duty with an honorable or general discharge and are eligible for VA benefits. The Department of Veterans Affairs (VA) has responsibility for providing federal benefits to veterans and their dependents. The VA health care system consists of over 850 hospitals and outpatient clinics (Department of Veterans Affairs, 2002).

What VA funds:
There are four potential ways to obtain AT within the VA health care system including vocational rehabilitation and education programs, prosthetics and

other medical supplies, grants for automobiles and automobile adaptation, and loans and grants for adapted homes or adaptations to existing homes (Protection and Advocacy, 2000).

Employment-Based Funding and AT

Vocational Rehabilitation and AT
Who they are and who is eligible:
The Department of Rehabilitation (DOR) in the state of California is the agency responsible for providing vocational and independent living rehabilitation services to people with disabilities. These services are available through the Federal Rehabilitation Act (Protection and Advocacy, 2000, p.7-1). and states that choose to participate in the program receive federal money to provide services and must operate under the federal mandate.

Assistive technology is a vocational rehabilitation service and eligible people can get the tools they need from DOR to achieve employment goals. Following 1998 congressional amendments to the Rehabilitation Act, rehabilitation technology includes telecommunications aids and devices, sensory aids and devices, and other technological aids and devices.

A person is eligible for rehabilitation services under the Act if:

- One has a physical or mental disability which constitutes or results in a substantial impediment to employment;
- One can benefit in terms of employment outcomes from vocational rehabilitation; "Benefit in terms of employment outcomes" means entering or keeping full-time or, if appropriate, part-time employment in an integrated labor market.
- One requires vocational rehabilitation services to prepare, secure, retain, or regain employment (Protection and Advocacy, 2000).

What DOR funds:
Just as Regional Centers determine what assistive technology is fundable by the Individual Program Plan (IPP), the Department of Rehabilitation will fund the assistive technology necessary to achieve employment goals outlined by the Individualized Plan for Employment (IPE). Assistive

technology services and items are available when they are necessary to help one become employable.

Rehabilitation technology is defined by the Rehabilitation Act as "the use of technology, engineering, or scientific principles to meet the needs of and address the barriers faced by people with disabilities. This can include education, rehabilitation, employment, transportation, independent living, and recreation." Rehabilitation technology is divided into three categories: rehabilitation engineering, assistive technology devices, and assistive technology services" (Hager, 1999, p.9). Assistive technology devices are 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" (Hager, 1999, p.8). Assistive technology services are any services that directly help a person to select, acquire, or use and assistive technology device such as an AT evaluation provided by an Occupational Therapist (Hager, 1999, p.8).

DOR and other Programs:
If a comparable service is available through another program, DOR is the payer of last resort for many services. The items must not be available through other free or less costly sources or through Medi-Cal, Medicare, or other funding sources including private health plans. It is also possible that someone who became disabled as an adult might see this program as a first resort- if they have no insurance. Because he or she was not a disabled child, does not have a developmental disability and might not be eligible for medical, DOR has a larger role to play. Non-disabled people are perhaps more likely to HAVE insurance but not a guarantee. This is easily seen when comparing the percentages of those who are non-disabled without insurance (57%) and individuals with disabilities without insurance (17%).

DOR as the funder of the loan guarantee program:
The California State Treasury has a permanent revolving fund called the Rehabilitation Revolving Loan Guarantee Fund. This program is available to eligible persons to buy vans, automobiles, and special equipment.

Loan Guarantee Eligibility:
Loans are available to those who are adults with a disability, the parent of a child with a disability, or the private employer of a person with a disability.

The individual must also be ineligible for vocational rehabilitation services or independent living services. However, the items purchased must be necessary for employment or to enable an individual to live more independently and a physician must certify them or by DR. Additionally this is a loan of last resort. The applicant must have been turned down by all other available sources before they are eligible to apply for this loan. Currently this loan is underutilized in California due to a high interest rate (13%) and an unwillingness of banks to participate for fear that they will have to repossess someone's AT device if they default on the loan.

Social Security Work Incentives and AT

Who they are and who is eligible:
Social Security itself does not provide any assistive technology, but has many work incentive programs that allow an individual to shelter income to purchase employment-related assistive technology so that benefits are not affected. The two social security programs applicable to people with disabilities are the Supplemental Security Income (SSI) and Social Security Disability Income (SSDI).   SSI provides a guaranteed grant to people who were disabled before they had a substantial work history, while SSDI is a federal pension for those who became disabled after working for some time and paying into the Social Security trust fund.

The three main work incentive programs that allow an individual receiving these benefits to access assistive technology are the Plan to Achieve Self Support (PASS), Impairment Related Work Expense (IRWE), and the Blind Work Expense (BWE) (Sheldon, 1999). The goal of Social Security's work incentive programs is to encourage people with disabilities to seek employment without the fear of losing their social security benefits.

What they fund:
While Social Security work incentive programs do not fund assistive technology, it is these programs that make it possible for a person with a disability to accrue money without being penalized in their income received by SSI/SSDI. Each of the work incentive programs has guidelines for the type of assistive technology available.

- PASS allows for the individual to deduct the cost of AT such as: the

equipment and supplies needed to establish and carry out a trade or business; equipment or tools needed because of a condition or for a job; modifications to buildings and vehicles to accommodate an individual's disability; and the purchase and maintenance of a private vehicle.

- IRWE is an expense for an item or service that is directly related to enabling an individual to work and is directly related to a physical or mental impairment. Examples of allowable deductions for IRWE include medical devices, prostheses, work-related equipment, residential modifications, essential nonmedical appliances and equipment, routine drugs and medical services, and certain transportation costs.
- BWE deductions do not necessarily have to be related to impairment, they can be any work expense if a person is blind. (Protection and Advocacy, 2000)

Barriers to funding AT through the various funding streams

The assortment of funding sources for assistive technology is uncoordinated, convoluted and incompatible often leaving the consumers of assistive technology to flounder in funding gaps and systemic barriers. Varying eligibility requirements due to age, type of disability, purpose, and need make obtaining the necessary technology to cover all the realms of an individual's life and life span difficult at best. For example, various California Children's Services only cover someone until the age of 21, or the Department of Rehabilitation is only a possibility if one is employed or seeking employment. The funding problem seems to be a reflection of three issues; the lack of coordination of the service systems involved, differences in the underlying assumptions about disability from within these various systems and, finally the unique connection between employment and access to health care in the United States. Mendelsohn (1997) stated:

> "*Vesting one agency or service system with the responsibility for meeting educational needs, another for vocational needs, and still a third for medical needs transcend the conceptual boundaries between system, or where they fall between the*

cracks. Perhaps nowhere are the inherent limitations proposed by current policy more dramatically illustrated than in the area of assistive technology. Devices provided by one system may need to be forfeited when someone comes under the jurisdiction of another, or the availability of needed technology from one may preclude the provisions of other needed devices by another" (p. 38).

Mendelsohn continues to state that there are three main reasons that assistive technology remains incomprehensive and inadequately funded including the following:

- The lack of a systematic reporting requirement for assistive technology services
- Non-uniformity in the characterization of assistive technology expenditures
- Lack of clarity between assistive and mainstream technology

These three reasons refer to the absence of a common language between the various funding agencies for assistive technology. The lack of a shared language makes it incredibly difficult to keep track of data regarding the use, funding, and satisfaction of AT. Furthermore, it leads to insufficient communication and understanding of the relationship between mainstream and assistive technology.

Deficit Model

"So long as we utilize program models that predicate access to assistive technology on the deficits arising from disability rather than on the values of technological literacy and use, this disparity will not be altered" (Mendelsohn, 1997, pp. 36).

An example of this deficit model at work is the "medically necessary" language used by Medi-Cal and private health insurance, and the qualifiers in place to access assistive technology through Vocational Rehabilitation. Essentially the provision of assistive technology is based upon an individual deficit in the person that requires something more qualified by the term "medically necessary" or in the context of the individual's vocational goals in order to be considered healthy or employable.

"The old perception of people with disabilities in society, which derives from the medical sciences, is based upon the assumption that disability is a physical or mental deficiency that is not desirable. Under this individual deficit paradigm, people with disabilities are regarded as in need of special care or services that will cure them or else help them to adjust to their 'affliction'"(Doe & Noakes, 2002).

The use of this deficit model not only reinforces the concept that people with disabilities are in need of assistance, but also allows the patchwork of funding sources for assistive technology to continue. An example of this is that a doctor or health professional must agree the desired AT is needed for medical reasons, even if the device is a captioning decoder so a deaf person can watch a television! It is somewhat out of the realm of medicine that someone may need AT to perform a job duty or listen to the radio. When the funding comes through a medical source; either through a private health plan or one of the government funded health programs, it forces the AT to be considered "medically necessary." The difficulty in obtaining funding however, arises in that individuals need AT not simply because it is "medically necessary," but because it is "necessary for life." In a Connecticut court appeal regarding Medicaid's denial of AT for an individual, the court upheld that the individual seeking coverage for an unlisted item of AT would have to show that the failure to cover that item through Medicaid "would make DME coverage inadequate to the Medicaid population as a whole" (Allan, 1998). Essentially if it's not on the list, then one must prove that everyone on Medicaid needs that item.

"As a practical manner, streamlining of AT funding is a challenge because there are so many players, each of which has divergent statutorily-defined objectives" (California Foundation for Independent Living Centers, 2001). To gain an understanding of the patchwork of funding sources for assistive technology, it may be helpful to examine the roles and goals of the various players in the game of requesting and denying funding for AT. It is clear that most roles are adversarial. For example, a consumer's goal is to obtain the needed technology to work, play or live more independently, whereas an insurance company's goal is to spend as little as possible and still comply with the law. From the insurance company's point of view, the most restrictive definition of a disability best serves their purpose. Hence, the industry adopts a medical model of disabilities that relies on a definition

based on "medical necessity." "We regard technology in society as a tool of great usefulness, but treat AT as a form of therapy or discretionary benefit that has to be justified" (Mendelsohn, 1996, p.36).

This is not a new issue in the funding of assistive technology. The different use of language in different programs was the main target of many of the recommendations from the 1993 National Council on Disability study. The call for a universal classification system and common data sets were recommendations based on the needs for common language regarding assistive technology and disabilities. It is only after this type of dialogue happens will there be the potential for a system of seamless comprehensive assistive technology that encompasses the health, educational, vocational, and functional needs of people with disabilities. The development of such data sets and a universal classification system will allow policymakers to better understand consumer needs regarding AT as well as to understand issues of cost/benefits that AT provides and promote a more seamless system of AT provision.

On the other hand, a funder may find itself in an adversarial position as to other funders (Mendelsohn, 1996, p.37). Medi-Cal, for example, may adopt qualification rules as to its payer position with regard to Medicare. The people with disabilities who are the lowest income earners are eligible for Medicare but often not eligible for continuing coverage with Medi-Cal due to income restrictions. There exists an economic difference between medical coverage for those who work and those who do not. For those who are unable to work, much of their medical care is covered by Medi-Cal, such as prescription coverage. However, for those who are employed, or the working poor, they earn too much money to qualify for coverage through Medi-Cal, but do not earn enough money to cover all their AT needs. These adversarial relationships do not bode well for the development of cooperation and coordination of agencies and may perpetuate persons with disabilities "falling through the cracks."

Health Insurance and Employment

Another issue relevant to addressing the gaps in funding for AT is the relationship between employment and access to healthcare. Approximately 72% of people who had insurance in the United States in 1999 were covered by a private insurance plan, 64% of which were plans (U.S. Census Bureau,

2002). However, specifically related to people with disabilities, it is important to note that approximately 22% of people with disabilities are unemployed (U.S. Census Bureau, 2002). This is a significantly lower number than was found in a survey regarding the use and need of assistive technology conducted by NIDDR, RESNA and the University of Michigan in 2001, (Carlson, et al, 2002) which found that 52% of people with disabilities were unemployed because of their disability.   In addition, a 2000 National Organization on Disability/ Harris Survey (Rossheim) found that only 32% of people with disabilities worked full or part-time compared with 81% of people without disabilities.   Specifically, in the state of California, Census data show that 54.9% of individuals with a disability between the ages of 25 and 64 are employed compared with 80.0% of individuals without a disability who are employed (U.S. Census, 2002). An even more alarming statistic related to workplace benefits, was that in 1997, it was found that 2.3 million people with disabilities who were actually employed, were without health insurance (Rossheim) meaning that they were working too much to qualify for state sponsored health care, but not enough to qualify for employer-based health plans. It is this kind of statistic that explains why so many people with disabilities are forced to make the choice between not working and keeping health care coverage.

One answer to this crisis is the passage of the Work Incentives Act, which allows people with disabilities the opportunity to earn more without fearing the loss of their government-sponsored health care as well as the option to buy-into Medicaid while earning up to 250% of the federal poverty line. This has yet to be phased into practice in the state of California. It is hoped that through passage of this act, more people needing assistive technology will be able to get it through employer-based health plans.

The Americans with Disabilities Act (ADA), which was passed in 1990 was another piece of federal legislation that sought to remove barriers to people with disabilities participating in the life of their community and in seeking employment. However, a major issue concerning this legislation as well as the Tech Act, is the lack of education and information regarding the benefits of AT and ways to purchase it that are not prohibitive for consumers. The findings of Carlson, et al (2002) regarding usage of AT and funding demonstrate two important points. First, the two main sources of funding, medically- based and vocationally- based, do not meet the need of

consumers using assistive technology in the larger community. Second, the majority of information provided about AT is based on health care providers' own experience; not only is their knowledge regarding the use and need of AT limited, but it is reasonable to assume that their knowledge about potential sources of funding for assistive technology may be solely medically-based.

Conclusion

Without an integrated systemic funding process that includes a universal definition of assistive technology, spans the lifecycle, and covers more than basic medical needs, consumers will be continue to struggle to obtain all but the most basic devices that allow them to live independently. Funding agencies need to expand the provision of AT from equipment and services that are "medically necessary" to that technology which will help individuals lead productive and independent lives.

AT Funding Sources in California

Program or Organization	Eligibility Provided	Services Provided	Assistive Technology funded	Additional Requirements
California Children's Service	Children and young adults 21 and under with certain medical conditions whose parents pay for some or all services. A referral is required.	Medically necessary benefits: equipment, tests, drugs which are required to meet the medical needs of a client. Services include evaluations and purchase of necessary assistive technology	Medical supplies, Durable medical equipment, medical appliances, electronic or manual communication devices. CCS also provides repairs, maintenance and upkeep of appliances and equipment.	You may also have to apply for Medi-Cal; Income limit of less than $40,000 annually. Authorization of AT is required before it is bought.
Medi-Cal	SSI get Medi-Cal automatically; People 65+; Children 0-21; blind or disabled people	Medical office visits, hospitalizations, dental/vision care, prescription medicine, mental health, substance abuse services, needed medical tests	Durable Medical equipment; Augmentative Communication devices; Prosthetic devices	Services must be medically necessary
Medicare – Part B	Age-based: 65+ years of age: Disability-based: received SSDI benefits for at least 24 months; end-stage renal disease	Outpatient hospital care; physician services, physical therapy, medical transportation, durable medical equipment, prostheses, and home health care for most people	Durable Medical equipment such as: iron lungs, respirators, hospital beds, wheelchairs, crutches, canes, inhalers, commodes, traction equipment, heart pacemakers, etc.	The equipment must be medically necessary. If the carrier finds a less expensive appropriate device, it will limit payment to the reasonable charge for that device.
Private Insurance	Membership in the plan; "medical necessity"	Medically necessary services and equipment as established by the plan. Each plan differs and does not set out clear list of covered services and limitations.	Durable medical equipment, prosthetic devices, or equipment associated with physical and occupational therapy	The health benefit plan should define medically necessary and set out what supporting information is needed. In addition, a specialist often requires a referral.
Regional Health Center	Under 18 with certain disabilities including mental retardation and related diseases, cerebral palsy, epilepsy, autism, developmental disabilities	Assessment, rehabilitation & training; treatment; therapy; prevention; special living arrangements; community integration; family support; crisis intervention; special equipment; transportation; etc.	The Regional Center develops an Individual Program Plan (IPP), which describes your goals and objectives and any technology needed to achieve them. The IPP must list any technology you need. Some examples of AT include: wheelchairs, hospital beds, communication devices, etc.	

AT Funding Sources in California

Program or Organization	Eligibility Provided	Services Provided	Assistive Technology funded	Additional Requirements
Social Security Income – Work Incentive Programs: IRWE, PASS, BWE	For those seeking employment – one must apply in person at the local Social Security office.	Allows recipients of SSI payments and beneficiaries of SSDI to keep cash payments or private resources that would otherwise be lost as a result of employment	No AT is funded directly, but recipients are allowed to keep cash/medical benefits they would otherwise lose because of employment	All income must be reported so save records of everything, forever.
Veteran's Affairs	Veteran with a service-connected disability	Vocational rehabilitation and education programs; Prosthetics and other medical supplies; Grants for automobiles and auto adaptations; Loans and grants for adapted homes and adaptations to existing homes	Items such as prosthetic appliances, eyeglasses, sensory and other technical aids.	
Vocational Rehabilitation	A physical or mental disability; Must be able to benefit in terms of an employment outcome from DOR services; Require vocational rehabilitation services to secure, retain or regain employment	Assessment to determine eligibility; Counseling & guidance; referral and other service to secure needed services from other agencies; job-related services including job search and placement; vocational and other training services; diagnosis and treatment of physical and mental disabilities; transportation; on-the-job assistance; interpreter services; occupational licenses, tools, equipment and initial stocks and supplies; etc.	AT needed for employment goals – the needed technology must be included in the Individualized Plan for Employment (IPE)	Currently there is an order of selection based on severity of disability

CONCLUSION

Is it working? A conditional yes.

After reviewing the issues of assistive technology in six major areas it can be safely answered "yes", technology is working for people with disabilities. Unfortunately, this only leads us to further questions because it is a conditional yes. The conditions include access to funding, adequate information, repair, training and services. Assistive technology works for some people, primarily those who have resources to purchase and maintain it. It works for some people who have access to training and can learn to use it. It works for some people who are members of the market that the industry is designing for. Many people are still not part of the consumer population using assistive technology. We want to learn more about why these people are not effectively using assistive technology. We also want to know why some people seem to access funding programs and equipment while others cannot or do not. There have been significant successes in how people with significant disabilities live, work, and learn using technology but we have only reached the tip of the iceberg. There is a potential to reach many more people who could benefit from assistive technology but to date have not been using it.

Michael Parker from Access Ingenuity, a member of the AT industry, sees the CR4AT project as an opportunity to discover a greater understanding of AT users. "The project is interesting because my focus is making AT more effective for individuals who use it. From the research, we get the chance to understand the wide broad-based analysis, a non-judgmental discussion re: AT."

Often people in the technology field speak of the "digital divide". This is the gap between the "haves and the have-nots" in computer and telecommunications technology. It includes people with and without computers and with or without internet access. There are growing concerns that as fast as technology improves and increases access for some people, a large portion of people are left behind and are further disadvantaged. People with disabilities are among the population at risk of being left behind.

We are also part of the new generation of technology users. People with disabilities, inventors, engineers, rehabilitation professionals, and researchers have led the way in terms of human applications for technology. People with disabilities are able to use artificial limbs, speech-to-text dictation, digital hearing aids, and electric wheelchairs driven with puff and sip technology. Our goal is to ensure that people with disabilities are part of ongoing research and action leading to empowerment and self-determination and that we are not left behind. We have a significant vested interest in the future of assistive technology

In February 2001, President George W. Bush announced the New Freedom Initiative. The New Freedom Initiative will help ensure that Americans with disabilities can access the best technologies of today and that even better technologies will be available in the future. At the core of this effort are proposals that reinvigorate the Federal investment in assistive technologies; improve Federal collaboration and promote private-public partnerships; and increase access to this technology for people with disabilities. Unfortunately, assistive and universally designed technologies are often prohibitively expensive. In order to increase access, the New Freedom Initiative will significantly increase funding for low-interest loan programs to purchase assistive technologies. In addition, innovation is being hampered by insufficient Federal funding for and coordination of assistive technology research and development programs. The New Freedom Initiative administration will provide a major increase in the Rehabilitative Engineering Research Centers' budget for assistive technologies, create a new fund to help bring assistive technologies to market, and better coordinate the Federal effort in prioritizing immediate assistive and universally designed technology needs in the disability community.

Assistive technology has the potential to make our lives much better. Susan Miller, executive director of Placer Independent Resource Services (PIRS) in Auburn, says, "Assistive technology is integral to independent living, whether it is a simple inexpensive item like a holder for playing cards, or more complex and expensive like a voice synthesizer. The information that we will learn from this research project will help manufacturers to design and produce products that really meet people's needs. The best ideas always come from the people who actually need to use the product."

In health, we have the right to access diagnosis, treatment and prevention services. In order to reach our potential in health we need access to information in accessible and appropriate forms, we need physical access to a range of services and we need equipment to be designed well enough to permit access by people in a range of physical situations. When we are sick, we need access to adequate services and when we are well we want to maintain our health and control our health service consumption.

In employment we need to have access to real jobs and real opportunities for growth. We need both access to training and work that suits our skills and goals. The workplace is increasingly diverse and we want to take our place as contributors in the national economy. Policy barriers need to be removed and technology needs to make our participation possible. Funding barriers, disincentives and incompatibility of equipment need to be addressed to ensure that technology can empower our workplace participation.

Some of us will not be fully employed but will be active participants in our communities. For independent living and community participation to be a reality we must have access to public spaces and services. We must ensure that the technology is available to help people go to recreation programs, religious institutions, community organizations, and their neighbors. Our community needs to be inclusive and technology can assist if it is made appropriately and affordable.

Regardless of the situation, people with disabilities need to increase their ability to function in a range of environments. Changes to both the environment and the person are necessary. At the level of universal design it is essential that access is built into equipment and buildings rather than added on later. For people with disabilities, their individual ability to function needs to be supported through technology that enhances rather than limits their capabilities.

This project is innovative because it uses consumers with disabilities as researchers to investigate the issues that are important to community members with disabilities. The project also supports collaboration with private organizations, professionals, and the business community.

"When I found out what this project was about. I jumped on the opportunity to participate," said Heather Walton from Disability Resources Agency for Independent Living (DRAIL) in Modesto. "I knew this would be a special project - persons with disabilities researching issues of disability."

For the last year, we've been concentrating on what we know about Assistive Technology. This is just the prologue to a remarkable story of the definition and impact of Assistive Technology in modern society. Over the next year, hundreds of people will share their stories through focus groups, interviews and surveys. Their participation in the research will create the next generation of data on this important topic. The information collected will help shape our actions, policies, and programs. This is an exciting time. The process is just beginning. With the first year of work behind us, we are now looking to the next few years and expecting more collaboration, more questions and many more answers.

Community Research for Assistive Technology must be watchful for trends impacting people with disabilities. While initiatives like New Freedom bring hope and resources, other actions are cutting valuable services. In California[1] this December significant changes were made affecting funding for children with disabilities, older adults with disabilities and services to adults with developmental disabilities. Technology may provide certain advantages in life but public policy still has an impact on services and access that cannot be minimized through technical aids.

After conducting focus groups and surveys with a diverse population of people with disabilities we can look back at this volume to see what we have learned. Will we be able to fill some of the knowledge gaps? Will the new information help us understand current patterns and inequalities? We want to use the new information to act in ways that support sustainable research skills and AT effectiveness among people with disabilities. With the launch of this book, and its dissemination among stakeholders, we hope to initiate change.
The cycle of research is in motion. With more knowledge, and more action, more people with disabilities will be accessing technology, participating in their communities, and contributing to the research process.

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MASTER PRODUCT LIST

The Effectiveness of Assistive Technology in Improving Employment Outcomes: What we know now

- **Windows XP**, Microsoft Corporation

The Effectiveness of Assistive Technology in Accessing Health, Wellness, and Medical Care: What we know now

- **Accu-Check Voicemate**, Roche Diagnostics-Boehringer Mannheim Corporation in conjunction with Eli Lilly and Company
- **Bennett Contour Mammography System**
- **Colorado Sports Cycle**
- **CompuMed Pill Alert**
- **EX N'FLEZ Arm/Leg machine**
- **HEARTalker Personal Trainer**
- **Pill Alert**
- **The Pill Dispenser**
- **PowerTrainer cycles**
- **Saratoga Cycle**
- **ScriptTalk Talking Prescription System**, En-Vision America, Inc.
- **Welner Table**, Sandra Welner, M.D.

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- **American Thermoform printer**
- **Atlas**
- **BAT Personal Keyboard,** Infogrip, Inc.
- **Big Mack Voice Output Communication Aid,** Innocomp
- **Braille 'n Speak**, Blazie Engineering
- **DigiVox,** Sentient Systems Technology
- **Discover Board** (http://www.donjohnston.com)
- **DynaVox** (http://www.Dynavoxsys.com)
- **Eloquence** (http://www.voicerecognition.com)
- **The Freehand System** (http://remoteability.com/unique/freehand.htm)

- **Gemini** (http://www.assistivetech.com)
- **GPS-Talk,** The Sendero Group (http://www.senderogroup.com)
- **Half-QWERTY Keyboard,** Matias Corporation
- **Head Master Plus**
- **Headmouse Trademark,** Origin Instruments
- **icommunicator** (http://www.teachthedeaf.com)
- **IntelliKeys** (http://www.intellitoos.com)
- **Intro Talker,** Prentke Romich (http://www.prentrom.com)
- **Isaac** (http://www.certec.lth.se/doc/technologyand/4_isaac.html)
- **Jelly Bean Switch** (http://www.ablenetinc.com)
- **The Kurzweil Reader** (http://www.kurzweiledu.com)
- **The Liberator,** Prentke Romich (http://www.prentrom.com)
- **Lifestand,** Independence Providers, Inc.
- **Magni-Cam**
- **Mastervoice**
- **Mini-keyboard,** TASH International
- **Naturally Speaking,** Dragon Systems, Inc.
- **Powerlink2**
- **Robotic Work Station Attendant**
- **SoftVoice** (http://www.text2speech.com)
- **Swell Form Graphics Machine II,** American Thermoform
- **Think and Link** (http://www.think-and-link.org)
- **Tonguepoint system,** IBM Trackpoint III Trademark
- **Touch Talker,** Prentke Romich (http://www.prentrom.com)
- **Touch window** (http://www.learningneeds.com)
- **Tumble Forms Stander,** Sammons Preston
- **Via Voice** (http://www.ibm.com)
- **Vocal Link Cellular Module**
- **Winsford Feeder,** Northcoast Medical, Inc.
- **WordWave** (http://www.wordwave.com)
- **Wyndtell pagers and relay**
- **X-10 Controller**