

AT Narratives from California

Community Research
for Assistive Technology
Improving Access Through Collaboration



How it



Works



*A publication of the
Community Research for Assistive
Technology Project*

Tanis M. Doe, Ph.D., Editor

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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 contact us at:

CFILC

**660 J Street, Suite 270
SACRAMENTO, CA 95814**

Phone (916) 325-1690

TTY (916) 325-1695

www.cfilc.org

Patricia Yeager, Executive Director

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California Foundation for Independent Living Centers:

Patricia Yeager, M.S., Executive Director

Tanis Doe, Ph.D.

Amy Noakes, B.S.

Myisha Reed, B.A.

Angelica Farias, B.A.

Eleanor Higgins, Ph.D.

Vince Wetzel, B.A.

Jennifer Mansfield, B.A.

Michael Newton

Jane Kryski, M.S.

Shannon Springmeyer, Assistant Editor

California's Independent Living Centers'
Executive Directors and their participating staff

Dayle McIntosh Center

Disability Resources Agency for Independent Living

Independent Living Center of Kern County

Placer Independent Resource Services

Rolling Start

Silicon Valley Independent Living Center

Southern California Rehabilitation Services

NIDRR, Department of Education

Steven Tingus, M.S., C.Phil., Director

Dawn Carlson, Ph.D., Project Officer

California State University at Northridge, Center on Disabilities

Harry F. Rizer, Ph.D., Director

Other Contributors

Winston Ching, California Deaf and Disabled Telecommunications Program

Dr. Michael Clark, Kern Regional Center

Sue Digre, PARCA

JD Hermann

Noemi Hicks, Asian Rehabilitation Services

Stacey Hiramoto, Sacramento County Division of Mental Health

Pam Hoye, Speech-to-Speech
Marcia J. Scherer, PhD, MPH, FACRM
Bob Segalman, Ph.D., California Department of Rehabilitation
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Foreword

*There is more than a verbal tie between the words
common, community, and communication.*

– John Dewey, 1916

John Dewey, philosopher and educator, believed passionately in democracy. He advocated the connection of education and experience and viewed the purpose of education as broadening and enriching experience. This fits well with Dewey's emphasis on learning environments. Education is not about universities and colleges but about learning to live life fully. Fully participating in life is the goal of the independent living movement and of the harnessing of assistive technology (AT).

Common, community, and communication are words that form the spirit and heart of Dewey's philosophy. These are also key words that we associate with the spirit and heart of participatory action research (PAR), or what is known more often in Europe as "emancipatory research." We can also add another word: Commitment. Successful PAR is a research methodology that involves commitment to a common purpose, namely that of researcher and participant in concert, or community, deriving finding of relevance and use in this case to the impact of AT in adding quantitatively and qualitatively to the capabilities and functioning of individuals with disabilities.

The findings presented in this newest publication of the Community Research for Assistive Technology Project (CR4AT) extend our view of where AT has added to the lives of its users and where it has also let them down in some very important ways. This book is not a critique of AT devices and services but a vitally important summary of current perceptions and realities and a foundation for a dialogue where we, as the AT community, can most fruitfully explore future research initiatives, device design priorities, service provision needs, and improved/additional ways for persons with disabilities to achieve their desired level of community participation.

There is apt to little action without communication. CR4AT has provided mechanisms for this: A feedback form included with this book, a newsletter, a web site, and additional avenues at public presentations, for example, for the on-going connection of AT researchers, providers and users. I hope that you will take advantage of these opportunities to work together to create a stronger community for each of us.

Marcia J. Scherer, PhD, MPH, FACRM
Director
Institute for Matching Person & Technology
486 Lake Road
Webster, NY 14580 USA
585-671-3461 (phone/fax)

Introduction

Narratives from people in California who have disabilities and use technology have provided the foundation for this book. We interviewed over 300 people about their experiences getting and using technology. Their stories help explain how assistive technology works for them, and how the system works for consumers of assistive technology. This book presents stories of success and failure in the areas of health, employment, independent living and function. We also discuss issues impacting ethnic minorities and issues of funding through the stories of people with vested interests in these areas. Although the focus of all the stories is assistive technology, analysis points out issues of personal assistance services, universal design and attitudes of the public and professionals towards people with disabilities. Stories are also provided of successes at the individual, service and policy levels that illustrate what could be replicated for other situations. This book can be used by consumers, families, AT advocates, industry professionals and people who want to learn ways to make AT more effective in the lives of people with disabilities.

Why Technology?

Technology is part of popular culture in the United States and around the world. Technology can be very expensive and accessible only to the wealthy or it can be very basic and available to almost everyone. As technology has been integrated into our society, people with disabilities have also developed an increasing interest in how technology can be made to assist them in daily activities. Low-tech devices such as special cutlery to eat and high tech devices such as eye gaze activated computers can all change the lives of people with disabilities.

Assistive technology is simply the tools and resources used by individuals with disabilities to help improve their quality of life. Assistive technology comes in many shapes and forms. It can be as simple as eyeglasses, hearing aids, knee braces or manual and power wheelchairs, or as technologically sophisticated as voice-activated computer systems. In addition to individual use of technology, systems and buildings used by everyone are being designed to accommodate a wider range of

people with and without disabilities. (California Foundation for Independent Living Centers, 2001)

The U.S. Government has recognized that technology is important to the lives, health, employment, and functioning of millions of Americans. “Let the shameful walls of exclusion finally come tumbling down,” remarked President George Bush the day he signed the Americans with Disabilities Act (ADA) into law in 1990. The ADA bans discrimination against people with disabilities the areas of employment, public accommodation, public services, transportation and telecommunications. Two years later, President Bill Clinton announced “We must not rest until America has a national disability policy based on three simple creeds: inclusion not exclusion; independence not dependence; and empowerment not paternalism.” (Justice for All)

What Are Disabilities?

This research looked at people with a wide range of disabilities—not just the most obvious disabilities such as physical disabilities. Many people have less visible disabilities impacting mental health, learning, speech, language or health. Lots of people have chronic illnesses such as diabetes, epilepsy, asthma and lupus that can cause significant disabilities. According to the ADA, disabilities include both actual impairments and perceived impairments. The ADA defines disability functionally as any condition that substantially limits major life activities such as seeing, hearing, walking, or working; it covers nearly 900 disabilities.

Why Do This Research?

While we have a good general picture of the importance of technology for increased independence and health, specific information about how technology impacts health, function, employment and independent living is not readily available. California is a state that represents a diverse population of people with disabilities from various age and ethnic groups. It is the perfect place to ask questions about the effectiveness of assistive technology (AT) because California experiences a wide range of access issues including economic disparities, insurance coverage, rural and urban living environments and varying linguistic access. Research conducted over the last year asked questions about how people got equipment and technology as well as what impact it had. The goal of this year’s project

was to collect enough information to paint a picture of how AT impacts people with disabilities in a range of situations. The details were gathered directly from the users of AT and the results will inform the next steps in action and research.

A Multi-Level Approach

Assistive technology supports disabled people at the individual level and at the systems level. At the individual level, assistive technology enhances function; at the systems (or public technology) level, technology provides access that enhances community integration and equal opportunity. This concept is part of the universal design movement and it also enables people to access their communities in addition to individualized technology. Despite the growing availability of technology to assist people with disabilities, there are still barriers to acquisition, maintenance, use and effectiveness of assistive technology. This project seeks to empower people with disabilities at the consumer level to directly participate in research that will increase their independence through AT.

“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. Often, technology on the systems level involves large markets and large businesses. Incorporating principles of universal design into the built environment, information technology and telecommunications, consumer products, and transportation can increase access to technology.”
(NIDRR, Long-Range Plan”– Technology for Action and Function Research)

What Is CR4AT?

Independent Living Centers (ILCs) across the state are members of a trade organization called the California Foundation for Independent Living Centers (CFILC). One of the grants that the CFILC has received is the “Tech Act” funding to operate the AT Network in California. This project provides the state with a free 800-telephone number for information and referral about AT, and also puts trained AT advocates into ILCs and gives support to consumers seeking equipment and technology. Using these skilled advocates and the

systems change advocates in the ILCs the CFILC developed a network of trained community based researchers. The Community Research for Assistive Technology (CR4AT) project partners with the AT Network and the members of CFILC to implement community based research on AT.

The CR4AT project has undertaken a broad research effort to look at the impact of technology in the areas of health, employment and independent living and function. In order to fully understand the system that surrounds the use of and access to assistive technology by persons with disabilities, CFILC researchers have elected to use a “participatory action” research design (Kemmis & McTaggart, 2000). By doing so, CFILC is uniquely able to investigate and report on both changes to the individual and changes to the environment. This represents a pioneering initiative, as it is one of the first times that community based researchers, trained by a consumer-directed organization, have implemented a major research grant from the National Institute on Disability and Rehabilitation Research (NIDRR).

The project aims to:

- Train independent living advocates in research techniques, so that they can collect reliable data in their communities regarding the use of AT.
- Focus particularly on the issues of AT for unserved or under-served minority communities and how they are or are not getting the information and services they need to maximize state and federal AT resources currently available to them.
- Develop credible comprehensive conclusions on AT use in California via sustained research in four priority areas: employment outcomes, health and function issues, technology for access and function, and integration among local Independent Living Centers and their communities.

Using an ecological approach, CFILC will actively involve people with a wide range of disabilities from various demographics to ensure the research takes account of important regional factors and attitudes that facilitate or impede the effectiveness of AT.

The goal of the proposed project is to increase the capacity of the independent living community to work with its members and stakeholders to collect research data on access and use of AT to improve the lives of people with disabilities. University researchers trained participants in research methods and assisted them with data collection and analysis. Community advocates have been

conducting focus groups, surveys, and action research in their respective regions. Advocates will also train university students to do community-based research related to AT and independent living.

The Research Cycle

This research is looking at both current use of AT as well as potential uses that will address health, employment and function barriers for people with a range of disabilities. It includes these consumers in the process to ensure their priorities are being addressed. The AT advocates of the CFILC network are primarily people with disabilities who use AT themselves.

During the first year of this five year project, researchers reviewed existing knowledge and literature about AT in various areas. The results of that research were published in a book called *Is It Working? A Review of AT Successes and Barriers*. The results also led us to determine which questions were key and should be asked in the focus group portion of the research. In year two we conducted the focus groups and the results are being published and disseminated via this book and other reports. The focus group research informed our survey design and project activities for year three. There is a continuous cycle of asking questions and acting on answers.

To gather qualitative data, multiple focus groups with a wide variety of populations were conducted throughout the state. Eight Independent Living Centers (ILCs) held three to four focus groups each. Focus groups averaged approximately 10 participants, with a range from as few as 2 to as many as 16. Meetings allowed for open submissions, either written or verbal, and required formal outreach to community organizations. A total of 333 individuals participated in the focus groups. Although we made an effort to reach more people, participants were limited to those who were interested and could attend the focus groups. The participants in each group shared at least one characteristic—either the use of AT, their type of disability, their employment status, their ethnic or racial status, or the type of AT service they used. This book represents the collection of analyses and recommendations that emerged from the focus groups with consumers in California. It describes how AT systems work for a range of people with disabilities. These narratives are stories told by people with disabilities in the research over the second year of CR4AT activities.

Research has been characterized as mysterious or academic and often irrelevant. We have tried our best to make sure this project is both relevant and understandable by AT consumers and stakeholders. We are open to your feedback and look forward to continuing discussions about the topics and the research. This project is community based and we see it as very much owned by those it impacts.

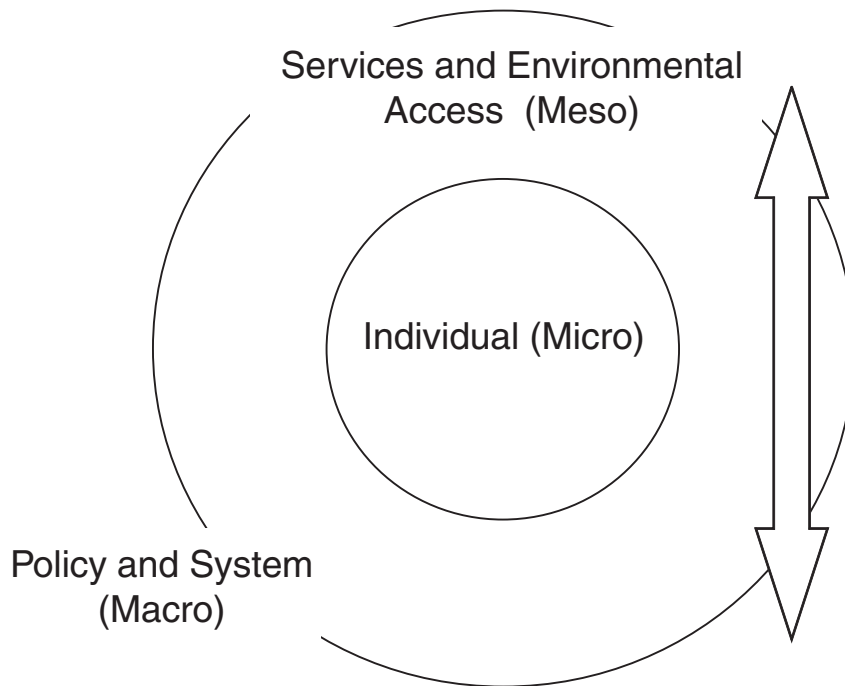
Patricia Yeager, M.S.
Executive Director
California Foundation for Independent Living Centers

Harry "Bud" F. Rizer, Ph.D.
Director
"Center on Disabilities"– California State University, Northridge

Methodology

Introduction to How We Did the Research

The Community Research for Assistive Technology (CR4AT) project uses an ecological approach to research assistive technology (AT) use in the disability community. The ecological model is composed of three levels that interact simultaneously—the individual level, the services/environmental level and the policy/systems level. The ecological model supports a holistic research approach that—“examines the complex challenges from every aspect and probes into the systemic issues at the societal, service and personal levels, and considers how the issues at these levels often intersect,” (Doe, Rajan, & Abbott, 2003). The selection of an ecological model to conduct community research implies that there is a need to investigate not only at an individual level, but to examine the environment and community in which the individual is embedded (Ferrari, 1998).



- Micro level: Individual, or the consumer, is the inside circle of the ecological model.
- Meso level: Services, such as DOR and vendors of AT, make up the middle circle.
- Macro level: Policy and System, including things like the ADA, laws and lawmakers, and societal attitudes, comprise the outer circle.

In the ecological perspective people with disabilities are viewed as part of an ongoing system of action and reaction; they are both actors and subjects. The ecological model views the environment as created by society but also as having an impact on members of society (Ferrari, 1998). Individuals within a community are influenced by it, but also participate in its creation. Using this interactive system's model (Senge, 1999) and the ecological approach, the researchers investigate issues at the individual and environmental levels as they impact people with disabilities and other AT stakeholders. Conducting analysis of the research data, the CR4AT project strived to look at all three levels to determine what was or was not working and where changes can be made effectively.

The project also employed a participatory action research (PAR) model. With this model, persons with disabilities play key roles in and have relevant information about the social system under study; they also participate in the design and implementation of the research.

What Is Participatory Action Research (PAR)?

A PAR model seeks to link the research process to the process of social change. A PAR model not only suggests conducting research to define the problem, but also to find solutions to problems once they are identified. PAR provides several benefits to those engaged as the community researchers. A deeper understanding of the work process is realized, as well as expanding the role of the community researchers within the context of the organization and the broader context of the research. In addition, community researchers are able to revisit their own practices and implement improvements or solutions on a larger scale.

Participatory action research means that people play key roles in and have relevant information about the social system under study, and participate in the design and implementation of the research. PAR recognizes the change process as a researchable topic. PAR is not only doing research to define the problem, but also to find solutions to identified problems.

In PAR, people with disabilities and trained researchers participate in the research process—but without the traditional division of labor between researcher and subject. Both types of participants have knowledge to exchange in the process. The more participatory in nature the research

becomes, with the support of professional researchers, the closer the research will come to serving the needs of people with disabilities as they define them.

PAR is most useful when knowledge relevant to research problems is distributed relatively widely. It is also most useful when there is a goal to alter a social or socio-technical system (Doe & Whyte, 1995).

The origins of PAR are in literacy movements and liberation theology. You may have heard of Paolo Freire who worked with poor people in Brazil. He was one of the leaders in believing that the people needed to take part in their own liberation. He believed that “Only the oppressed can liberate themselves—not the oppressors” (Freire, 2000). In the development of the independent living (IL) movement, a concern was raised that people with disabilities were not directing the services that they used or needed. Professionals were making choices for or on behalf of people with disabilities. The IL philosophy supports the empowerment of community members to take an *active* role in their own lives. PAR is one of the many tools that communities can use to support their own development. PAR has been used for consumer surveys, needs assessments, community development, advocacy, skills training and equipment development. Action research has the advantage of combining investigation with improvement of services so that the consumers involved can actively participate in learning about the system or issue and then take a role in making change happen (Hart and Bond, 1995).

Research Design—Collaborating With the ILCs

Research is about using a systemic method to find answers to questions. We start with what we know, plan and ask questions, seek answers, and then act on the findings. We reflect on what we know again, then plan and ask more questions, and act on these questions.

In the first year of the CR4AT research project, six papers were produced to summarize what we already know about assistive technology in six areas: independent living, function, health, employment, funding, and AT for ethnic minority groups. When CR4AT developed the list of potential research questions gleaned from the position papers, collectively titled, “What We Know Now,” we had far too many questions to be able to actually accomplish a thorough investigation of all of them. To determine what the community considered priorities among the identified areas that needed further research,

the CR4AT project took a well-known research method, the community concerns report method, and adapted it into a survey, the Community Concerns Report Questions, to have our stakeholders—Independent Living Centers and people with disabilities—identify the focus our project should take.

We distributed the Community Concerns Report Questions to 28 executive directors of the Independent Living Centers in California, as well as the 42 AT advocates at these centers asking them to identify their top priorities. It was our intent to use the community concerns report 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.

In addition, we conducted several preliminary focus groups at several major conferences in California with a variety of people: people with disabilities, employers, vendors, and AT manufacturers. Participants elaborated with issues that had been missed or clarified what they felt were the most important priorities.

During our preliminary focus groups, project researchers realized that we needed to add employers as a key stakeholder group beyond our original targets— consumers, the AT industry, service providers and funding sources. With these new developments, we were better able to set our priorities for the rest of the project as we continue to study our four main priorities: employment outcomes, health and function issues, technology for access and function, and independent living and community integration. With this feedback we were able to identify key issues to be investigated in our second year through conducting focus groups in the communities.

Advocates as Researchers

Thirteen members of Independent Living Centers, who were either systems change advocates, or AT advocates were trained to conduct participatory action research, and in particular, how to moderate focus groups in a thirty-hour training seminar held over four days.

In addition, the CR4AT project held initial trainings at the statewide meetings of ILC executive directors in January and June 2002, inviting all those interested in learning about the research project. At these trainings the basics of

participatory action methods, the priorities of our project, and research ethics were discussed. CR4AT delivered two more trainings on PAR and focus groups in July and September 2002.

Some major points in the moderation of focus groups included the reiteration that conducting a focus group is not journalism and because it is research the researchers should not lead answers. In addition, much of the training conducted focused on actively listening to the participants and delving deeper into responses given.

Many of these advocates have disabilities themselves. All work directly with people with disabilities as AT advocates, systems change advocates, or other capacities in their respective Independent Living Centers. In their roles as advocates, they provide information and referral on AT to disabled consumers in their communities. They provide consumer referrals to qualified AT professionals for evaluations, assessments and training on AT, as well as help in locating vendors, services and funding resources. In addition, they inform the California disability community about AT through outreach to the communities they serve.

It must be acknowledged that with these models, researchers view the topic filtered through personal histories and values. In the course of the focus groups, our community researchers used their experience, biases and prior knowledge regarding AT and employment to further address the barriers people with disabilities face in employment. One way in which the community researchers on this project brought their personal histories to bear was through their own experience as persons with disabilities who also use AT. Community researchers encountered many of the barriers identified from the focus groups. Both community researchers and participants in the focus groups in this study were members of the populations most knowledgeable about the need for AT and most directly impacted by the use of AT—people with disabilities (Mertens, 1997; Patton, 1990). Another way that personal histories and biases may have influenced the research was through the process of analyzing and coding comments made in a focus group. Personal experiences may have determined how the community researchers prioritized important emerging themes from the focus group transcripts.

Recruitment for Focus Groups

Forty-three focus groups were conducted with 333 consumers who use AT. Various disability and ethnic minority groups were targeted as well. These included Spanish-speaking consumers, Native Americans, African Americans, and Asian Americans. Specific disability groups that have been traditionally under-served in California were also sought out to participate and provide information in the focus groups including the deaf and hard of hearing, blind, seniors, those with psychiatric disabilities, persons with developmental/ cognitive disabilities and speech and communication disabilities. In addition, the focus groups also targeted those persons with disabilities who live in rural areas.

Participants in the focus groups were provided a cash incentive to participate. We wanted to provide cash to our focus group participants, because there was concern that if they accepted a check for participation, then their benefits through Social Security Disability or a similar program would be affected. In addition, it promoted the concept that we were emphasizing: no benefits or services from the Independent Living Centers would be tied to participation in the research project as a focus group participant. All participants were guaranteed confidentiality. All participants were required to sign an informed consent form, wherein we stated, “No services from an Independent Living Center, the CFILC or any other agency will be affected by your participation in this research. We want you to understand that no penalty or loss of benefits will occur as a result of not participating or of withdrawing at any time. This means that you are a ‘voluntary’ participant and that you will not lose anything by refusing to participate.” Protection for participants in research projects is required of all federally funded research. A group of professionals called the Institutional Review Board (IRB) reviews the proposed research to determine if it is worth the risk to the participants. Our IRB was through California State University at Northridge.

During the focus groups, we learned how difficult it is to convince people to come to a focus group for “research.” For some, transportation was a problem, as well as the time of day the focus group was scheduled. Others were not interested, and needed to be convinced of the merits of the project in order to get them to attend. Some of the researchers had ingenious ideas and held their focus groups at a restaurant where lunch was provided *after* the focus group. The community researchers tried as much as possible to conduct the

groups in the communities that were participating, such as at senior centers, peer support groups, American Indian reservations, and churches.

Research Principles

The National Research Council (2002) has suggested several principles to identify scientifically based research. The research must be:

- Driven by significant questions
- Empirical in nature
- Theory based
- Designed around a sound linkage between the research questions and the research method
- Based on clear inferential reasoning
- Capable of being replicated producing similar results, and
- Available for professional scrutiny

The research being done through CR4AT meets these criteria and demonstrates relevance to the community members. Originally, the proposal for the research emerged from CFILC's interest in AT and the questions were developed out of trainings and meetings held with advocates for AT located at various ILCs in California. The type of research done in year one involved taking stock of what was already known, but this year the research was original and empirically based. Interviews and focus groups were done with a cross-section of people with disabilities to ask about their experiences with AT. The work was grounded in participatory action research (PAR) and ecological systems theory as well as responding to theories of occupational, vocational and independent living approaches to disability. The project is a five-year, action-oriented design that was built on the cycle of research and action coming from the PAR methodologies. Community and university researchers coded the qualitative research that resulted in this book, with a high degree of inter-rater reliability. The intent of the coding was to establish a system that could be duplicated by others and would reach similar conclusions. Our research has been made accessible to the community for review on the Internet, in hard copy and various other formats and this book represents an effort to further disseminate the findings.

Quality research is also defined by the consumers of the research, which in our case are both people with disabilities and people who work with AT. People are usually most concerned with: A) Does it relate to me and a need I have today? And, B) Can I access it, use it, and benefit from it (Westbrook, 2003)? We want to ensure that this research relates to people working in the AT industry and particularly to disabled people who use or want to use AT.

Methodology for Data Analysis

Each focus group lasted 90 to 120 minutes. Data was captured using audiotapes and hand-written notes. Moderators also submitted focus group summaries to the research staff upon the completion of each focus group. We had over 100 hours of audiotape and hundreds of pages of transcripts.

Research staff transcribed all spoken utterances on the tapes that were submitted. Less than 5 percent of the tapes had small portions of content that were unusable due to poor sound quality and/or difficulty differentiating voices. However, note takers were present at all focus groups, and if a taped transcript was unavailable or incomplete, the notes were used to augment the transcript. Transcribed statements were coded using “emergent themes,” short phrases that summarized the content of what had been said in the comment. Each comment was also sorted into one of the following topics predetermined by research staff to be of importance to the study: employment, function, health, independent living, funding or special populations. Research staff and moderators coded, rearranged, and prioritized the statements from each transcript using the method Krueger and Casey (2000) termed “the long-table approach.”

A methodology of grounded theory and progressive focusing was used to analyze the raw data (LeCompte, Preissle, & Tesch, 1993; LeCompte & Schensul, 1999). At the start of the project, staff suggested 15 emergent themes that were collected into a “code book” and disseminated to all coders. More emergent themes were added and disseminated as codings progressed so that once all transcripts had been coded, there were 67 standardized emergent themes. This was done to insure that similar content would be coded uniformly. Some of the focus groups had sections selected randomly to test for inter-rater reliability; for others the entire transcript was used to test. Only one focus group was not used because the information gleaned was not pertinent

to the study. Only 4 percent of the focus group transcriptions were not tested for inter-rater reliability. Thirteen percent of the focus groups were only partially tested for accuracy. Seventy-nine percent of the focus group data was analyzed in its entirety. Three researchers coded each transcript: the moderator of the focus group, a researcher who had not been present at the focus group, and one of the principal investigators. The inter-rater reliability for the coding of utterances by three researchers was 69.55 percent.

There is a major difference between the coding process and the analysis process. Coding identifies the themes, similarities and patterns in the transcripts, while analysis describes the meaning interpreted by the researchers. Together the community researchers, CR4AT staff and university-trained researchers worked to gain an understanding of the meaning of these focus group discussions (Silverman, 2001). When we decided what to include in this book we took the advice of Krueger (1998) who suggested that we keep in mind the purpose of the project, the audience of the report and be sure the results are understandable. We wanted to ensure that people who read this book are able to come away with a clear understanding of the effectiveness of AT and the narratives that support these findings. We also are aware that research tends to be inaccessible to people without university training, so we have tried to use plain language.

The Impact of Focus Groups in the Disability Community

Focus groups not only provide a qualitative source of information for a research project, but also encourage community interaction with the participants. We found that the focus groups encouraged peer support—when someone was having a problem with AT, be it funding or finding it, others in the group were always happy to share what had worked for them. In addition, the focus groups were an educational experience for many of the participants. They learned more about what the ILCs provide in their communities, and they learned that they could advocate on their own behalf. In addition, the focus groups were a great resource for networking. In one group, the moderator was asked how she had obtained her guide dog, and she was able to provide resources to the participant. Moreover, the focus groups were a friendly environment where people with disabilities were able to socialize and make new friends.

Many of the community researchers found that their focus group participants were—“talkative and eager” to share their experiences and any information

they could provide. We found that for many it was the first time someone had asked their opinion about what they saw as the barriers and solutions to the AT system they lived with every day.

Why PAR Works for Us

Focus groups are particularly appropriate for this type of qualitative research, in part because the candid discussions generated can help us understand both the individual and systemic barriers faced by persons with disabilities.

“Participants can qualify their responses or identify certain contingencies associated with their answers. Thus, responses have a certain ecological validity not found in traditional survey research” (Stewart & Shamdasani, 1990, p.12). In addition, focus groups are appropriate when trying to understand differences in perspectives between groups of people, and it is desirable that these ideas emerge from the group rather than from individuals (Krueger, & Casey, 2000). Focus group data can then be used to generate a theoretical framework or to confirm or challenge hypotheses. Focus group results can inform policy and practice in fairly rapid and direct ways. (Krueger, & Casey, 2000).

The key here is that the people with the most at stake in the issue have a major role to play in the implementation of PAR. PAR is a key to the future success of independent living for persons with disabilities. Individuals with disabilities, the ultimate consumers of AT, need to be involved in every aspect of the research and development that leads to AT. In PAR, individuals with disabilities are involved in setting the research agenda, developing research questions, participating in the research as researchers, advisors, and consultants, testing research ideas, and most importantly, evaluating the results of the research.

PAR is more than a methodology because it describes an approach to doing research, not only the methods of doing particular types of PAR. Many NIDRR-supported engineering centers embrace the PAR approach. For example, consumers may screen devices submitted by inventors. Consumers and researchers collaborate on projects in consumer engineering laboratories. The need for user involvement in AT research is an opportunity for collaboration among researchers and consumers internationally to explore the impact of consumer involvement on the vitality of the research agenda and on the validity and replication of the research process.

Learning From Experiences

Stories From the Field

by Tanis Doe, Ph.D. and Janie Kryski, C.R.C., M.S.

What Did We Learn?

CFILC has had a unique experience with the Community Research for Assistive Technology (CR4AT) project. This project was funded to be a research project rather than an advocacy or services project. In order to become capable of conducting the necessary research, CFILC had to develop skill sets among its existing staff and the staff of Independent Living Centers who were members of CFILC. The training that was provided to the ILC staff was customized to suit the needs of both the research project goals and the accessibility issues of people with disabilities. Not only was this project designed to interview and survey people with disabilities who use AT, it was also developed with the express intent to involve people with disabilities as researchers. A few of the trained researchers were asked for their comments on what they learned. In addition we have summarized some of the learning that has resulted from participation in this project. Our hope is that people undertaking a similar project will read what has been learned and reduce future difficulties through our experiences.

Several of the people who have been trained by this project came in with no preconceptions about research. We expected that some people would have a pretty negative view of research because of the history of disabled people being subjects of medical research. We also thought that some people would be cynical that people without university degrees could learn the necessary skills. However many people were very open-minded and had not really thought about research as an issue until this project started. Some of the people being trained did already have university degrees and some already had a taste of what research was. One community researcher shared that she had “research background from my graduate work in sociology, ‘soft science’ and in speech and hearing science, ‘hard science.’ Therefore I knew the difference between qualitative and quantitative research methods.” Additionally, this same person also had a performance background and said, “I looked forward to moderating focus groups, because I feel very comfortable in front of

people. I was a teacher, so I felt confident that I could guide the discussion and keep it on track.”

It certainly made a difference in training when people came with some skills and aptitudes already. We had people who spoke multiple languages, people with technology backgrounds, as well as people with disabilities who knew a lot about their community resources and the unmet needs. All of these areas of knowledge contributed to the ability of CFILC to conduct community research in a positive way. This does not mean it was not without challenges. We all went through struggles.

Our project used participatory action research (PAR) as an approach to designing the research cycle. But in this research the focus was not just on people with disabilities, it was on users of assistive technology. In PAR it is important to involve the people who are affected by the research in the conduct of the research. Some of the staff at the office were users of AT but most importantly some of the community researchers were also users of AT. One researcher reported, “Yes, I have extensive knowledge of AT; my personal background, unrelated to this project, helped me.” Another said, “As an AT user, I felt very comfortable sharing my AT story with the focus group participants, who in turn, also freely shared their AT stories with me. I felt that my being an AT user gave me an extra degree of credibility with the participants.”

This concept of credibility is particularly important for working with marginalized or underserved people. We knew from the beginning that gaining the trust and respect of the people we wanted to interview would require development of relationships over time. But as with most research projects we had little time so we wanted to start with people who already had some established ties to the community. Some of our researchers were AT advocates and others were independent living or systems change advocates. These positions gave the staff a lot of contact with the community. But as we found out, even that contact was not enough. The individual participants in our focus groups were often members of communities who already had some ties to the local ILC or to disability organizations. We were successful in bringing in people who we already knew, who already had a sense of who we were and for whom our community researchers had some creditability. Being disabled, being experienced with AT, and being a member of the community, made a big difference in recruiting people. These advantages reached their limit when we

tried to reach people who did not really know us or the Independent Living Centers. On the basis of PAR principles, having people who know about AT, and who also had disabilities, made a major difference in supporting the goals of identifying AT issues for the various populations and topics involved in the project.

Making the research process accessible was part of our commitment when the grant was awarded. It was not going to be enough to make our website accessible and print the reports in large print, and make captioned versions of any videotape. The research process started with the orientation and training and then the data collection and all of that had to be accessible too. The principal investigator is Deaf as well as a wheelchair user so all the trainings needed to have ASL interpreters and wheelchair access. Other members of the community research team were also wheelchair users and some were blind or visually impaired. The research training needed to be accessible, but so did the actual data collection in the field. This required we make some effort to accommodate and ensure participation was not impeded during the process. One of the community researchers reported, "I had to request that all materials be provided to me in .txt or .doc format, so my screen reading software could fully access the information. Next, I made Braille cue cards, so I could stay on track with the questions during the focus groups. I used the services of an assistant to drive me to some of the meeting sites, which were located throughout the tri-counties. We compiled all the signed consent forms, and filled out the expense paperwork to receive the incentive money prior to the focus groups. I typed in my notes on my accessible computer, and e-mailed them to the office."

We had several events where an assistant was present not simply to run the tape recorder or be of support in handing out paper. Often the assistant was a key player in making the focus group accessible to both the community and the facilitator. In more than one occasion there were different disabilities present and some of the disabilities in the participants might make it difficult for the facilitator who had a different disability. For example, if a person leading the focus group was hard of hearing and a person participating in it was a person with a speech impairment, the assistant could repeat the words again making sure the content was understood.

After our experience with 12 community researchers interviewing people with a range of disabilities, we thought we would have much learning to pass on to other researchers interested in doing disability research. It turns out that most

of our experience was not unique to disability research. That is, our ideas and experiences are relevant to all forms of community research. One researcher said, “Be clear, concise, to the point. Many of the questions posed were too wordy, too lengthy.” This is good advice for any focus group. It seems even with pilot focus groups and practice runs, it is still important to simplify questions and to ensure that the language is appropriate to the population—not just the topic. One point we can make is that we should have taken more sessions with the group of interviewers to get more input from them on wording so that we had more direct community input earlier on. We had two trainings but most of the time was used in teaching the facilitation technique and the principles behind focus group research. It would have been useful to spend some more time developing the questions and simplifying the wording with the community researchers who would be doing the facilitation.

Recruitment was another area that posed a barrier for us, and helped us learn. As with almost any research, it is pretty difficult to convince people that your issue is worth their time and effort. Since there is also some history about research between community members and researchers, it was probably more difficult to try to get participants to attend the focus groups we conducted. In addition to the normal problems, there were barriers in transportation, communication, and trust that made it especially hard. One of the community researchers described her experience:

“I was not prepared for the extra work involved in recruiting participants for the focus groups. Even with the \$40 incentive money, scheduling several groups turned out to be a huge undertaking! I cannot suggest any solutions to this difficulty.”

The lack of suggestions indicates the seriousness of the problems because even after 40 focus groups there was no agreement on what would have worked better. Many people used the network they already had established through their jobs as advocates at the local ILC. This meant we did get a good sample of people with disabilities who used AT but also meant we had a much smaller sample of the underserved populations and people who were not connected to the local ILC.

We also were concerned that we were not being accessible or appropriate enough and that there may be unnecessary barriers remaining that could be removed. One of our researchers felt the issue was primarily language and access to vocabulary especially for people with lower literacy. Another researcher related a story of her focus group with Deaf participants.

“I described my interesting focus group session with 10 Deaf participants, who all communicated to me their utter amazement that I could function so independently with low vision. Since Deaf persons depend so heavily on their eyesight, and since they usually say exactly what they are thinking, I felt a little bit like the main attraction at a freak show. I noted that some persons with disabilities are just as capable of ignorance and uninformed attitudes as other, non-disabled people. I recognize that there is a tension between the blind and Deaf communities, based on our mutual dependence on a respective compensatory sense. My focus group with the Deaf folks was a baptism by fire for me. The ASL interpreter was nearly overwhelmed by the rapid-fire pace of the discussion, because everyone insisted on talking at once. I was unaware of their constant interruptions, because I could not see their sign language, and the interpreter had to voice a mile a minute to catch as much of the cross-talk as possible! It was a circus, but I had fun anyway! I felt bad for the person who had to type the lengthy transcript of that focus group! So, my words of wisdom would be to get as much of an orientation about the cultural aspects of a particular disability group before jumping in with both feet like I did. I recognize that I learn best on the job, but it would have been better if I knew that I could be more firm with the Deaf folks, and I could have expanded the ASL interpreter’s role to make an accommodation, by informing me when the participants were cross-talking, so I could step in and be a more effective moderator. Despite the roughness of that group, I feel that all of us came away with a better understanding of each other’s disabilities.”

One of the other researchers was a Deaf person and did a focus group with people who had a mixed range of hearing loss. Although they generally were not signing they were all talking at once and often not hearing each other. More time was spent repeating and clarifying what someone had said so that the other Deaf person in the group would know. Without this form of accommodation everyone was saying the same thing and not knowing it. Also, there was certainly a cultural difference between the Deaf facilitator of the group and the Deaf people in the group. Most of the participants used assistive listening devices, hearing aids or cochlear implants, but the leader used sign language. The transcript for that focus group was probably very difficult to produce!

Cultural awareness, orientation, sensitivity and selection of suitable facilitators will probably make a big difference in future projects. We would definitely want a Spanish-speaking leader for a Latino group and try to avoid having to use an interpreter. There is both a cultural and linguistic benefit to having a Spanish-

speaking leader in a group who primarily uses Spanish. But in contrast, if we had an ASL user who was leading the Deaf focus group, there would be no sound to audio-tape. If the participants and the leader all used ASL there would be no record of the discussion. The option of videotape is problematic because of having to move the camera very fast to follow the discussion and the way it breaches confidentiality. Having an interpreter (or two) makes sense for this population and provides a verbal record of the discussion. If there was a different purpose for the focus group and if we could use a note taker who was fluent in sign, then it might be possible to hold a focus group all in ASL, but it really does depend on the purpose of the research.

This project focused on the staff who were already employed by ILCs as the potential community researchers. We did not look beyond the member organizations of the CFILC to consider bringing other community members into the project. One of the reasons, and barriers, was money. We did not pay the participating community researchers because they were already on staff at their respective ILCs. The ILCs did get an incentive to participate but we did not have additional funds to pay people as individuals to be researchers. This may have limited the group of researchers we trained to those already in a position of some advantage, having a job.

People with disabilities are still seen to be consumers (by mainstream professionals). Even when we are university educated, if we have disabilities we are consumers of the disability system. But our own researchers do not necessarily think like that. To produce this book we asked some of the researchers about CR4AT's experience in training consumers to do research and one of them said, "Did we train consumers to be the community researchers? I thought most of the researchers were staff of the ILCs as I was." Some researchers did not classify themselves as consumers, differentiating between consumers as community members and consumers as all people with disabilities in general.

Another researcher who was asked the same question replied, "I think it would be great if future consumer researchers would be required to read this book about our experiences, so they know what they are getting involved with! I believe that our core group of researchers had a passion for the goals of the study, and a courageous streak that compelled us to overcome the challenges and follow through with our commitment to the research. Those qualities are necessary for future researchers to have. A case in point are a pair of researchers who, despite one being laid-off and the other having his hours cut in half, continued with the project. Finally, the support of my ILC was crucial for

me, without which I would not have been allowed to devote the block of time I wished to this project.”

One thing we can learn from this experience is the importance of commitment— both individually and organizationally. Success depends on having people who really want to do the research and want to do it well. Having the organizational support for time, resources, and outreach makes all the difference. Universities are often able to dedicate a “center” or an “institute” to just do research. ILCs are too busy just serving the crucial needs of their community to be able to just focus on research. The CFILC has shown leadership in believing that research is a tool, that we can learn from doing research and translate it into advocacy and services. The commitment shown by CFILC helped to encourage member ILCs to also make the commitment, and this proved quite worthwhile. Now the trained community researchers are quite capable of applying their skills for evaluation purposes, to learn from their communities, and to design future research projects that meet their organizational needs. Much has been learned and there is a lot left to learn. The more you know... the more you realize you still have to learn.

Micro AT Success Story

From the Assistive Technology Journal,
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by Jennifer Mansfield, Staff Writer

When Laurie Hoirup, Executive Director at the Community Access Center in Riverside, moved from her home in San Diego County to Desert Hot Springs, she had to adjust to many different things, including a new city, new neighborhood and different weather conditions. Although she welcomed the move, some adjustments took longer than others and some took her outside with a garden hose as her showerhead.

Hoirup uses many different kinds of assistive technology (AT) and has severe mobility impairments with very limited use of her hands. She is in a powered chair and requires a caregiver for most of her daily activities, including bathing.

Before she began work at the Community Access Center, Hoirup experienced challenge after challenge as she completed her move. When she lived in San Diego, Hoirup had a roll-in shower and a shower chair that worked great for her, rolling directly into the shower. However, her new home had a bathtub and shower doors, making her old shower chair unusable. Despite the absence of a shower chair, Hoirup excitedly moved into her new home with her husband, and because she had an old hydraulic shower chair, she was able to bathe in the tub. However, the seals were broken and the chair had to sit on an ice chest to remain stable. Hoirup's husband or her male attendant had to carry her from her bedroom into the shower and place her on the stationary chair in the tub, unlike the one that she knew that she needed.

Shortly after moving into her new home, Hoirup attended the Abilities Expo in Southern California in search of a more ideal shower chair. In addition to the convenience of a new chair more suited for her needs, sheer necessity prompted Hoirup's quest; her husband was not going to be able to be at home to help her in and out of the shower due to work. She was also in the process of hiring a new caregiver and desired to have a female rather than a male. Thus, it was even more important she have a new chair since a female caregiver would not be able to carry her in and out of the shower either.

The search for a new chair proved rewarding as Hoirup found a great chair for \$1,200. The chair ideally suited to Hoirup's needs and her home's features had a stable base for the bathtub and wheels so she could be moved from the bedroom to the bathroom. Once hooked to the base, the seat of the chair can slide over the wall of the tub and into the bath. The shower chair vendor worked closely with Hoirup and her insurance. In February of 1999, the vendor submitted a request to see if Medi-Cal would pay for the device. The vendor had to submit a letter justifying why Hoirup needed this particular chair along with other requested information. Hoirup knew that it would be a while before she heard back from Medi-Cal and remained patient.

In May of 1999, Hoirup had to hire a new caregiver and chose a woman, as she desired. But with that came the inability for Hoirup to be carried in and out of her shower chair as previously done. In addition, Hoirup still hadn't heard from Medi-Cal. So, without any other choice, Horiup began bathing outside on her patio.

As Horiup continued to bathe on her patio with her water hoses, she finally heard from Medi-Cal in July. After waiting six months for a response, Horiup was told that her request was approved as modified and they would fund a roll-in shower chair, one she already had and was useless in her new home.

Through personal contacts, Hoirup was able to obtain the phone number directly to the field office, which is normally not given out for obvious reasons. "I told her that I already had the chair they approved and I needed the one I requested," said Horiup. "I explained that I was bathing on my patio and once it gets cold I wouldn't be able to."

It was explained to Hoirup that they would again review her request and contact her with their decision. One month and a half later, Hoirup's shower chair was approved and she received it in September, eight months from her initial request and five months after she began showering on her patio.

Hoirup's education, work experience and natural advocacy skills have led her to much knowledge in AT and personal advocacy. Hoirup was able to personally take the steps that advocates at the Independent Living Centers are trained to take for consumers. Because she did her homework and stayed on top of things throughout her journey, Hoirup reached her goal of obtaining her new shower chair. Hoirup commented, "In college I discovered advocacy and learned to be my own advocate; it just came naturally."

Living with Disability and Technology

Independence and Community Inclusion

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

Background

Almost 10 years ago, according to a National Center for Health Statistics report, approximately 17 million people used at least one assistive technology (AT) device (1997). If we look around at today's society, we notice there are many people who use assistive technology: some children with muscular dystrophy rely on wheelchairs and/or walkers to help them be more mobile; temporarily injured people may use crutches to help them recover. Many seniors use grab bars in the bathtub to help prevent falls; and some athletes use assistive technology such as ankle supports to aid rehabilitation and prevent further injuries. Citizens of all ages increasingly rely on technology in every aspect of life: home, work, school, play, and community. For most people technology makes life easier and broadens horizons, and for the young provides an earlier start to learning (National Council on Disability, 2000).

For people with disabilities, however, technology changes the most ordinary of daily activities from impossible to possible (Scherer, 1996). The opportunity to obtain assistive technology and utilize its potential should not be denied.

Since the 1940s persons with disabilities in North American society have been treated by service providers who worked under the concept that doctors, social workers, and occupational therapists are more knowledgeable about a person's needs than the person in question. This expert model based on the medicalization of disability denied the consumer an active role in their treatment and rehabilitation. The independent living (IL) model challenges the traditional support model where consumer empowerment is minimal and places an emphasis on people with disabilities being self-directed and making their own decisions about situations that directly impact their lives. Although it began in Berkeley, California in the early 1970s, the IL movement has been developing over time with influences from people with disabilities across the United States (McDonald & Oxford, n.d.)

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 life 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 (Doe, 2002).

The concept of independent living is integral in breaking down the barriers that people with disabilities have faced for many years. When persons with disabilities are encouraged and able to make decisions concerning their own lives and their own welfare, this results in the inclusion of persons with disabilities in society.

Through the use of assistive technology, persons with disabilities are more active and involved in their communities than ever before. They are being moved out of institutions and into their communities or staying in their own homes evading an institution, because of the availability of community services and devices that enable them to live more independently. For some people, living independently does not mean living alone; it means living how one wants. Clearly there is a range of abilities among individuals that belong to the population with disabilities. Some people will need more assistance, technical or human, than others. Both types of support should be available.

The people interviewed for this project were asked questions about how AT was acquired and how useful it was. We were able to recognize issues around independent living in many discussions that were not specifically focused on independent living. The analysis we conducted provided important insight into the role of AT in the lives of people with disabilities.

What Types of AT Are Being Used to Increase Independent Living?

Numerous types of AT that aided independent living were mentioned in the focus groups. Mobility aids such as wheelchairs, walkers, canes, scooters, and modified vehicles were used. Participants used a variety of aids for daily living, which included grabbers/reachers, tape recorders, knee pads, coffee guides, rubber mats, pill cutters, shoe horns, and automatic can openers.

“I have a ‘Say When.’ I call it a finger-saver because it’s a thing you put in your coffee cup and when you pour it just gives you the right amount of depth so that coffee isn’t all over the floor. It takes any liquid—you put it over the edge and start pouring and it buzzes when it is close to the top so you won’t overfill it.”

Computers were also used to help conduct activities of independent living. Many participants used their adapted computers to connect with their communities and others with disabilities. They were also used to pay bills, write letters, research AT and disabilities, and other activities. Types of computer adaptations that were common were screen reading software, such as JAWS, voice recognition programs, like Dragon Naturally Speaking, text enhancer programs, such as Zoom Text, modified computer mice, larger screens, and specialized keyboards.

For communication, popular items such as cellular phones, phone amplifiers, text telephones, and pagers were cited. For those with visual disabilities, Braille devices, magnifiers, CCTVs, talking devices, audio books, and white canes were mentioned. Hearing aids, text telephones, closed captioning and visual alarms were frequently mentioned items for those with hearing disabilities. Durable medical equipment, like shower chairs, was also important in aiding those with disabilities to live more independently. Home modifications were also named as enabling people to live in their homes; grab bars, ramps, railings, and painted sidewalks were cited. While it was not surprising to learn what AT was being used, it was validating to learn how mainstream devices were being used to enhance independence in addition to specialized devices.

AT Impacts Independent Living Outcomes

The focus groups confirmed that AT is successfully used to aid in independent living and community integration. Persons in the focus groups repeatedly reported how they used AT to help them conduct daily activities in their home, such as watching TV, reading a book, bathing, cooking and cleaning. People were able to connect with their communities, enabled by AT to participate in activities such as driving, grocery shopping, visiting with friends, and entertainment, and succeeding at school and in the workplace. It was also noted that AT was not only functional but served the purpose of creating an environment for persons with disabilities where they could interact with others in their homes and communities, feeling safe, comfortable and free of pain with

the use of AT. It was also reported that AT provided a sense of socialization, increased mental health, and overall productivity was enhanced.

AT created a sense of independence and stability. People experienced fewer falls, remained healthy, less dependency on others to get and do things for them, and boosted their confidence. Activities cited using AT included being able to do one's own laundry, dressing one's self, writing checks and letters, parenting, cooking, completing homework, being mobile, vacuuming, and a myriad of other activities that people without disabilities take for granted.

"I do the cooking at home most of the time and I have lots of things for cooking. I have used an alarm timer that we have on the oven. I also painted my front steps; I painted them white and put green stripes on it, so I can see the steps."

AT has a positive impact on emotions, mental health, and self esteem. There is a psychological impact on a person who is able to use AT to accomplish activities that were previously not possible because they did not have the proper AT. Technology provided a sense of self-worth and capability to users of AT. The desire to rely less on others and the ability to conduct one's activities independently is a socialized trait in many Americans. The California Foundation for Independent Living Centers does not want to suggest that people who are dependent on others will have low self-esteem, but rather that many people who are unnecessarily dependent can be made more independent through AT. People who used AT also liked to feel less reliant on others and to be able to do things themselves. The focus groups revealed that it was possible to be more independent in their activities when using AT.

"I had [a] prosthesis and it was very helpful to me. I feel more powerful by myself."

A sense of security and safety for the focus group participants was seen with the use of AT. Persons felt less likely to fall and injure themselves when using AT such as a cane, walker or even a reacher. Visual alarms, such as fire alarms for deaf and hard of hearing people, were cited as safety devices used that provided persons with disabilities a sense of personal safety that we all need.

Social interaction through the use of AT was a critical component that research uncovered during the focus groups. Participants cited the ability to interact with their peers and get out into their communities by using AT. With various

devices, people were able to connect with their communities and interact in ways that non-disabled people do, such as shopping, eating out or visiting an art gallery, and other forms of local entertainment.

“The motorized wheelchair allows me to spend time with other people and go with other people in their van other than riding alone. If I had just the scooter, I could not pick people up and I couldn’t do things; I would be driving alone going to meet somebody and I could save wear and tear on my car and gas with shared driving. I know some people hate going into the wheelchair because it makes them feel more disabled. And for me, I feel like I could stay with a bunch of people in a group and it was actually more stable and the wheelchair also allows me to be more efficient and go shopping with my daughter.”

Productivity levels in daily living activities increased with the use of AT. It was seen that people were able to complete their homework and succeed in educational settings. It was also visible that communication, employment, and general skills such as writing and reading were increased due to the result of the use of AT. AT creates a level playing ground on which persons with disabilities can compete or maintain productivity levels with their non-disabled counterparts. People with disabilities felt physically less exhausted, and were able to maintain and increase their energy levels, thereby increasing their level of productivity in areas that many of us do not find to be tiring, but those with disabilities may find exhaustive. There are also many types of disabilities that involve significant fatigue. This can impair a person’s ability to function and makes AT even more necessary.

“Oh yeah, it makes a big difference now than it did then because I remember when I didn’t have a power chair I had a manual and I was driving a car, it took me twice as long to get in and out; I had to pull the chair out and get that together and going places was a lot slower. Now I ride in the van and my energy level is up. Those are the types of things that have increased my productivity and my energy level as time goes on.”

While discussing the benefits of assistive technology, many participants addressed the increased access to school and education from the use of their equipment. Programs such as Dragon Dictate and Kurzweil allowed users to be engaged and successful students.

“This is my first semester where I feel successful; I have attended college for five semesters non-consecutively and I felt as though I wasn’t quite where I could be so I feel as though it has enriched my potential because I have adaptive technology and I don’t have to wait for someone to read to me or for a tutor to proof read my work, I can do it on my time when I want, to my standards.”

The Internet served multiple purposes for those with disabilities. It was a means of communication with the outside world, provided peer support, and a resource to locate employment and for further self-education. E-mail was a means of communication and community access. The World Wide Web served as an information source for personal, business and school needs. People were able to search, store and retrieve information through the Internet and use of their computer adaptive hardware and software. This is one area that we plan to research further to see how people are able to use the Internet and what barriers remain to full access.

People with disabilities are often a disenfranchised, underserved population. Due to limited incomes and a lack of community accessibility, the Internet provides a means of connecting with others in similar situations, it provides an alternative way to be employed or self-employed and overall creates an equitable playing field where disability does not have to be mentioned unless relevant.

As one consumer expressed:

“We think that computers are so important to people that are hard of hearing that our chapter of SHHH [Self-Help for the Hard of Hearing] is going to have a training class for all of our members on how to use the computer.”

Using AT to Access the Community

AT provides a means of social interaction through community integration for people with disabilities. Through the use of AT, people with disabilities are able to participate actively in their communities by visiting with friends, obtaining employment, entertaining themselves and generally participating in society. Isolation is caused not by disabilities themselves but by inaccessible environments, difficulties with transportation and attitudes. Isolation that is both social and physical can impose great hardships on people with disabilities. For

many years, people with disabilities have been marginalized because of the fact that public places were not accessible. Much of that has changed, but not enough.

The benefits of assistive technology are not limited to functionality, but encompass increased community access and socializing. With AT of all types, consumers were able to venture out of their beds and their homes to travel, access community services and increase their levels of independence. Issues of community access were frequently mentioned in relation to increased quality of life. For example, an electric wheelchair not only increased one's level of mobility, but it also enabled going grocery shopping or visiting the library. The benefits of AT devices exceed the functional outcomes expected by medical professionals, providing the users of AT with increased capacity in areas beyond the basic functional necessity for which they require the AT.

Although access to our communities should be guaranteed to all—including basic medical care, information and education, health-promoting activities, and community services of all kinds—it is denied to many people with disabilities. Many different obstacles block disabled people's access to community services and activities. These obstacles include financial hardship, insurance coverage limits, lack of awareness among consumers, and many other barriers.

As one consumer revealed:

“My hearing dog helps me out when I go to restaurants and hotels, but they refuse my dog, I call the police to come, they tell them they have to let my dog in and that is when the owners accept it... how do I reply to them?”

When options to community access are not available, consumers can become confined to their homes and be forced to depend on their loved ones for their daily living needs.

“You stay home and hope that your intestines don't move [because you cannot get up to go to the bathroom].”

On a day-to-day basis, many people are faced with the lack of public accessibility. Public restrooms are not marked properly and medical offices, including their equipment and services, are not accessible. Participants called for measures to address these problems, including better advocacy and

increased official oversight. Even with the ADA there are still issues of non-compliance and the onus is on the disabled to fight for access instead of the proper pressure on the community/businesses. Even with a successful lawsuit, the person with a disability has to wait extended periods of time to see access provisions made into reality, and for many people, this waiting period is too long.

One participant suggested a way people with disabilities could get involved:

“We need a team with a video camera; the thing is to go evaluate these places. Our evaluation doesn’t mean anything unless we can really find these puppies and make them understand that it is just plain economically feasible and cost effective and to go ahead and do the right thing. They are not just going to do it just because we say so.”

Consumers also reported negative personal experiences when working with the public. Even though it has been over ten years since the passing of the ADA, disabled people still face blatant prejudice. It was stated that the general public does not know how to interact with people with disabilities, resulting in inappropriate statements, actions and discrimination.

This consumer cited a particular experience of discrimination:

“I have a store by my house and the manager refuses to fix the store wheelchairs. He told my mom one day that if we are handicapped we don’t belong in the store.”

Areas That Impact Independent Living Outcomes:

While it was evident that AT aided many in increasing their independent living outcomes, there were several areas brought to the attention of the project that have a negative impact on independent living outcomes. Transportation, housing, in-home support services and financial needs were all areas that concerned the focus group participants.

Transportation:

“Well I can do more. I’m not worn out when I get somewhere so I can go places. It’s been a long time since I’ve been down here [the

ILC]. Access¹ has been a big help for me because I can go from my home to the exact location where I need to go and don't have to worry about how I get there once I get off the bus stop. Whereas with the manual wheelchair, I'd just be worn out by the time I got there."

With the advent of public accessibility requirements, many persons with disabilities are able to utilize their public transit systems to engage interactively in their communities. Public transportation provides many with the means to interact in their communities—individuals have gained a greater freedom to go to work, go to school, go to the movies, and more.

Although great strides have been taken to improve public transportation, transportation still proved to be a problematic area for those wanting to access their communities. Many with disabilities must utilize the public transit system, emergency services, or demand-responsive transportation services such as Paratransit or Access. Accessibility of public transportation, the costs of the rides, the attitudes of transportation providers, and the limited routes provided by these systems were all cited as barriers to accessing the community for people with disabilities. This ties into the perspective that looks at both AT on the individual level and AT and universal design at the community or services level. Not only is AT used in homes but it is part of the wider community access system.

For those who use demand-responsive transportation services such as Paratransit or Access, services sometimes just don't show up, leaving the person with a disability stranded. Or the service will pick up but is hours late, causing a disruption in plans or causing a person to be late to doctors' appointments or work. For those who rely on these types of services, this disruption greatly impacts their abilities to access the community effectively. For example, one consumer was forced to drive despite being legally blind, jeopardizing safety because transit was not reliable.

Others who use the public transit systems in their areas relayed that many of the bus lifts are not accessible and cannot accommodate larger wheelchairs. It was also stated that the bus drivers do not wait until the person is completely

¹ Access Services is a demand-responsive transportation service in Southern California. People with disabilities are able to contact them and reserve rides in their areas.

sitting down or ensure wheelchairs are strapped in before driving off, which poses a safety hazard.

The public transportation system is almost nonexistent in rural areas. The rural focus groups revealed that people hitchhike to get to needed services, such as doctor's appointments or just don't go at all because they do not have the means to get where they need to go. When a person does not have the ability to get to medical facilities, work, school, or even visit with friends, their sense of belonging to a community is missing, leading to exclusion and a lack of socialization that others take for granted. This disproportionately affects poorer people who are living in rural areas- particularly Native Americans on reservations and migrant workers/people of color who are not living in urban areas.

Accessible / Affordable Housing:

The lack of accessible housing was a common theme that emerged in the focus groups. Participants expressed a difficulty in obtaining accessible and affordable housing. Respondents felt that current home manufacturers were not being realistic in their building practices, and that many deny the fact that the majority of the population will be disabled at one point in their lives, and will need accessible housing. Persons with disabilities recognize the need to build accessible housing from the onset, versus spending countless dollars to fix the problem later down the road. Many of the focus group participants were trapped in their current housing situation because it was the only place they could find that met their needs of accessibility. Additionally, it was often all they could afford.

Consumer solutions emerging from the focus groups to aid in solving the inaccessible housing issue were to enact universal design practices in building. Participants felt that if universal design was more widely known and enforced, it would help ease the difficulty in obtaining accessible housing for persons with disabilities. In several of the focus groups, seniors were the most adamant advocates of the universal design philosophy.

One participant noted:

"It would be helpful if builders would use universal design features in construction of housing. We need more education for the

builders and designers, and it should be mandated as a law if possible. I know some places where they have enacted universal design laws for new construction.”

Environmental access is imperative for independent living. While many devices are available to aid someone to remain in their home, their homes must also be accessible. For example, entrances, doorways, and access to the restroom are all barriers that can be overcome through the implementation of universal design features during initial construction. However, if housing must be retrofitted to incorporate no-step entrances, wider doorways, and accessible bathrooms, then the cost can be more than it would to move. Independent living means that our homes must also be able to include us.

In-Home Support Services:

Focus group participants used personal assistance of varying levels. Participants disclosed that they use their family members for their personal assistance needs. Activities relayed included transportation to and from the doctors, trips to the grocery store and more. In-home workers served other participants with their activities of daily living, such as bathing, eating, dressing, and running errands. For some respondents, in-home supportive services were too expensive for people to pay, and the hours that were paid for by other funding services did not fully cover their needs. In addition, many of the caregivers were under-paid and it was difficult for those who need in-home supportive services (IHSS) to locate qualified workers. Many people had family members who could no longer work because care-taking activities had become a full-time job.

One respondent noted:

“The other thing I have a problem with, is my in-home services. I had to require a new worker; I made twenty calls to them to get the paperwork for my new provider, it was something so simple just to mail me out the forms and the time sheets and I started calling, she said she mailed it out. Finally my boyfriend had to drive me down to pick them up. I called my worker eight times and she never called me back, then I got pushed off onto another person who I tried calling for a month...No call back, I called the supervisor and still no call back.”

In-home supportive services have been on the minds of persons with disabilities for many years. During research focus groups, IHSS came up when talking about the lack of funds available, and a service system that needed to be more in tune with consumer's needs. Although IHSS is not considered AT, it is a viable issue that Californians with disabilities are advocating for better and improved service to. For more information on the fight for improved IHSS services, please visit the CFILC website (<http://www.cfilc.org>).

The Bare Necessities:

More than AT, people are in need of the basic necessities: housing, accessible transportation and money to meet their needs. It was evident that many participants had high levels of financial need. Many of these people not only had AT worries, but also were concerned with basic welfare needs, such as food, medical services, etc. It was found that many participants did not use AT because they had more pressing needs with their funds, which included paying for medications, paying for food, paying rent, and utilities. For many of the focus group participants, AT was a need very low down on their list. Basic necessities proved to be more pressing issues than the procurement and use of AT.

When AT Is Broken

We wanted to learn more about what happens when equipment is taken away or not available for use, either because it is broken, needs repair or is in the process of being replaced. By not having the proper equipment, not only is productivity negatively influenced, but also health and function are adversely affected. This issue arose most when consumers' AT had broken down and needed repair or replacement. Broken-down equipment or equipment sent out for repair or replacement can place an undue burden on the person with a disability who relies on that equipment to perform well in their every day activities.

People reported they "could get by" without their AT, but that there was a significant impact on their functional levels which in turn affected their independence. When a consumer's AT was not available, due to repair or other reasons, lifestyle, freedom of choice and movement was adversely affected. People experienced higher personal assistance needs, lost much of their mobility both in the home and in the community, became housebound, and suffered a psychological impact on their well-being. For many participants, they expressed that life without AT was not a real life at all.

One focus group participant said:

“My wheelchair was out of commission several times and trying to get someone in to repair it has been quite a chore and getting it back is also. I can’t get around, I am just stuck at home, and even in the house, what am I supposed to do without a chair? Roll around, scoot, and crawl? But when they go out [for repair] it is really hard, you are out of luck. I wish there was something we could do to make that better.”

Coping strategies were important in learning how to live without AT that was broken or unavailable due to repair. Consumers had to make sacrifices in order maintain some level of functionality and independence. Communication was adversely affected along with mobility and the ability to conduct the activities that people were used to doing themselves.

According to another focus group participant:

“If my hearing aid or listening system breaks then I read lips and that is all I can do because nothing else works.”

Malfunctioning AT devices not only affected functionality, but affected a consumer’s independent living. When devices broke down, consumers’ actions became limited because being out in the community was made more difficult. This makes it very important for these devices to be repaired promptly.

“I don’t think they [insurance] are in touch with our reality; even if the devices are starting to die they will rather wait until it is totally dead, before they want to do anything about fixing it. If the insurance would just replace the AT when it is time, life would be easier. It costs them more by waiting for the machine to break totally down than if they would just maintain them.”

Strategies for Success

We also asked people what they wanted to change. The looks of devices, portability, ease of use and compatibility with other products were all areas for improvement that many focus group participants agreed on. Consumer choice was also a big factor for successful and continued use of AT. Focus group respondents wanted to see more devices universally designed and for persons

with disabilities to be included in the design process of devices so that manufacturers and vendors were creating products that met their needs. Lastly, advocacy played a major role for many in acquiring the AT that best met their needs.

AT Aesthetics, Portability, Ease of Use and Compatibility:

During the focus groups, the look of AT, the portability of AT, ease of use and compatibility were recurring themes. People wanted devices that did not make them “look” disabled; they wanted devices that could be taken places with them, and devices that did not take a “doctoral degree” to operate. In addition, it was found that compatibility with other devices was a common barrier for many. Many devices people were using, such as computer hardware and software were not compatible with other devices they were using.

Consumers felt better about using stylish and decorative AT and devices available in various colors. Traditional AT devices were seen as plain, old, and institutional. People discussed the improvements of AT in comparison to the past, such as the size reduction and improved usability of hearing aids, along with simple preference for other devices.

One participant relayed her experience:

“My social worker... said, ‘Why don’t you get a quad cane?’ and I said, ‘First of all, I think they make you look infirm, because of the color of it and the stiffness of it.’ I was told it would be more sensible to look for a sexy quad cane as opposed to keep on falling, so I bought myself a bronze quad cane which was really very stylish.”

Focus groups identified a need for devices that are portable. The devices that were cited as favorites by many of the respondents were portable devices. Portable AT allows the user to travel to various areas and still be able to utilize their devices. The participants want greater strides made in the AT industry to streamline and create more portable devices for their use. Laptops, personal digital assistants (PDAs), pagers and cell phones with text messaging, lightweight wheelchairs, magnifiers and other devices were commonly used that met their portability needs. Portability was seen as an issue that needs to be explored by more AT manufacturers. For many, AT can only be used in one location or in limited areas. This was seen mostly with text telephones for the

deaf, optical screen readers for the blind and visually impaired and computer technology.

The ease of use was an important factor for focus group participants. The most commonly favored AT devices in the focus groups were the ones that were lower-tech, simple to learn, and easy to use and maintain.

One participant confided:

“I have a talking wristwatch. It’s pretty handy because my car doesn’t have a clock, but when I’m driving, all I have to do is push a button to know what time it is. It also has an alarm, when I work in the yard, it reminds me that I must do something; it also has an announcement every hour.”

Other devices, although useful, required much more effort to use and sometimes, additional training was needed or an extra adaptation required to use the device properly. Intricate and complex equipment was habitually spoken of as more of a headache to the user and causing an increase in their stress levels, rather than alleviating it. Focus group participants shared that they no longer used the devices given to them because the device was too difficult to use and not compatible with their needs.

A respondent stated:

“Yes, there’s a program called Dragon [Naturally] Speaking where you speak into it and it starts typing—voice recognition. And it is a nightmare because you have to train them. They [the manufacturers] are going to get there, but right now they still haven’t gotten it down.”

It was found that people’s assistive devices did not work well with other equipment. Much of the AT available is made by different manufacturers and is ever changing, so that compatibility and upgrades prove challenging for many users of AT. Compatibility was an issue that was particularly evident with hearing aids in all of the focus groups. We heard numerous times that people did not have a good match with their hearing aids, that they did not fit comfortably, that hearing aids produced a squealing noise that created headaches, other physical discomforts, and that hearing aids set off security

devices in stores and were particularly incompatible with telecommunications equipment such as cellular phones.

One hearing impaired participant said:

“I just had this happen last week, and my hearing aid went out on Saturday night and I have all these devices, and nothing will work if my hearing aid doesn’t work and the T-coil doesn’t work.”

AT Choices and Changing Needs:

The ability to personally choose the AT device was something highly valued by respondents. People are able to make their own decisions about what works for them and what does not. However, the funders and service providers are still insisting they know what works best for consumers. A few participants were able to decide what equipment and options they wanted for their new devices. Others however were forced to take what they did not want and more often than not, the person abandoned the device.

The following participant described how he/she had to maintain a fight and keep refusing equipment until he/she received the equipment that met his/her physical and personal needs. His/her story exemplifies the unjust assumptions that exist, presuming a person with a disability is asexual and alone and will never have a partner, or even a friend over.

“Well, all the insurance would pay for was a twin bed. I had used a full-sized bed previous to that and I was used to it. To be quite frank, I had envisioned not being in bed alone. I wanted to have room for somebody else. So I kept advocating for a full-sized bed; and they kept saying, ‘No, no, no. You can’t do that’. And twice, they actually came to my house and tried to deliver me a twin bed!”

With every major purchase we make in life, we conduct research on it to make sure it meets our needs; we comparison shop, we physically handle the device. With many AT devices, these choices do not exist. Focus groups exposed that they would like to have alternative choices presented to them rather than just accepting what they are told they need. The lack of consumer choice in obtaining AT reduces the level of involvement a person with a disability has in accruing the device that best meets their personal, financial and functional needs.

“Well, I really liked the way I had the choices presented to me, so I could dislike the machine or say I like it. [I want to be able to ask myself] Is it a machine that I’m able to use? So I want to let you know that those choices are very important to a person who has a disability.”

As circumstances in peoples’ lives change, so do their technology needs. Both financial and personal changes in participants’ lives forced many of them to adapt the types of technology they were using. Some people talked about what they would do if they were no longer able to use their technology, and how they would cope. Others tried to prepare for the future when choosing the AT they would need.

“I would definitely look at all my options. I am not the type to just stay at home and not do anything; if I did that I would go absolutely insane. I would look at friends and other technology, I would look at everything that I could possibly do, to sit there and enhance that and hopefully come up with some other alternatives. It is important to me to get up, go to work, have a vehicle for my family also; I would have to relocate where I live, there’s a lot of things that I would have to do but I would do it.”

Universal Design and Inclusion Make a Difference:

Universally designed products were needed by participants in several of the focus groups. Participants felt that the resources exist to create devices that are accessible to more persons as well as readily acceptable by the general public. However respondents also felt that the AT manufacturers are not willing to create more universally designed products because as the devices become more popular and common, the demand would rise, thereby creating more competition and in turn lowering the price of devices as well as the profit margins of the manufacturers and vendors according to the laws of supply and demand. Participants observed that devices available in the general market could be obtained for a much lower price than “specialized” AT serving a limited market. The implementation of universal design practices, making a larger range of commonly used products accessible to persons with disabilities, would bar the need for consumers to buy higher-priced specialized items.

A few participants felt many of their problems could be solved if service providers, vendors and other AT stakeholders were to work with the disability community. Adopting a practice of inclusion would create a dynamic where the disability community/AT users tell the providers their needs and wants and the providers deliver by creating devices that meet their needs.

“They should ask people with disabilities what features they need and want—not just do the minimum standards or code.”

Other areas for improvement included better accessibility for people with visual, hearing and learning disabilities. Suggestions included better lighting and talking features in public places. Also suggested was spending money on curb cuts instead of signs saying there are no curb cuts, visible lines on steps for those with vision problems, and lower service counters.

“If I were a person who couldn’t hear at all and somebody is chasing me and challenged me and started talking and I couldn’t hear them, I’d go into complete panic from not knowing what is wrong, especially in today’s environment with the terrorist activities. A person with any type of hearing problems at all could be shot before anyone knows what is really going on, which is why the technology has to be spread to the public so that when an alarm system is built the people who designed that system test it to see if it will affect other AT like hearing aids and other devices.”

Better Devices for Parenting:

Parenting is a vital role for many. The focus groups found that some parents were able to obtain adaptable equipment to care for their children. Examples included a walker with an attached car seat and adaptive baby cribs. However, many parents also had a “wish list” of devices that could further assist them in performing basic activities in their care. A few parents discussed difficulties bathing their children and wanted a piece of equipment where they could bathe their children on a table or kitchen counter or in something that was height-adjustable. Other parents desired equipment that would allow them to transport their children easier.

“My power chair folds but where I’m lost is I have a three-year-old who is getting taller and taller by the minute and he was riding on my lap when we would go places and now it is getting too hard for

him to sit in my lap and I can't attach the bike seat to the back of it because my chair isn't heavy enough and it will flip back, so I don't really know how to get him around other than on my lap."

Information/Education Needed:

Focus group participants identified an information gap related to the knowledge of available assistive technology. People were unaware of the programs, devices and options available to them. Throughout the focus groups the need for better information and education was a common barrier that requires action to overcome.

A response from a key informant interview:

"Some have been successful in the use of AT, feeding, mobility, communication, and with computers. I think a lot of people we serve, not only just those with disabilities but families, are not aware of potential of AT. They don't deny disability, but have never confronted the fact that AT will help."

Other participants spoke of the importance of public education. These issues were especially related to equal access to public places, such as disabled parking and movie theaters. Consumers with disabilities want the general public to be aware of issues of the disability community so they are more accommodating. AT is useful but it doesn't solve everything and changes need to be made on many levels to fully include people with disabilities. Education is one of the ways that people with disabilities can be fully included and more empowered.

Advocacy / Action Needed:

In the quest for AT devices, people have encountered many different obstacles. Having a person available who knows the system and is willing to help them through the process is beneficial and almost always leads to success. An advocate can help the consumer navigate difficult funding streams and service channels. Through their experience, an advocate can help to make the acquisition of new AT devices and services a reality. Respondents felt there needs to be better and increased advocacy for persons with disabilities. It was believed that there exists a lack of understanding of the system for consumers

with disabilities and a lack of advocates who can help consumers navigate the system.

One focus group participant stated:

“I think better representation, someone to fight for the disabled. We are less than third-class citizens, or worse.”

Another commented about certain populations being ignored because they did not have the proper representation.

“I am very concerned that a small part of money nationally for AT seems to go to people with those disabilities that have the most advocacy skills. I see that as unconstitutional and a violation of our rights.”

The majority of the focus group participants were self-advocates. They had not found persons to aid them, so they took it upon themselves to struggle through the system to ensure their needs were met. People with disabilities are asserting their natural rights and striving to be seen by the mainstream society as no longer marginalized. Throughout the focus groups, CR4AT heard that people had to take matters into their own hands to accomplish their goals of obtaining services and AT devices. People are no longer settling for what others tell them what their needs are, but rather asserting themselves and making their own decisions that greatly affect their lives.

“I self diagnosed myself, I chose what would be most beneficial to my needs.”

Even though we are reporting the results of focus groups, it is important to note that California has a trained group of advocates in every Independent Living Center that work specifically with consumers to obtain the AT they need. The needs of the community have begun to be met through these AT advocates. However, we found that during some of the focus groups, participants were unaware that they could obtain the help of the AT Advocate at their local Independent Living Center.

Conclusion

The CR4AT focus groups confirmed what we already knew—that AT *does enhance* independent living and community integration. Devices allow persons with disabilities to remain in their homes and conduct a variety of activities that otherwise would be made extremely difficult or impossible. There exists a direct connection between AT use and physical and psychological benefits. People are happier when they are less fatigued; and when AT decreases pain and discomfort, they are able to do the things they choose. As the concept of independent living comes into maturity, so will the acceptance of using various low to high-tech AT devices to aid independent living outcomes.

Functionally Enhanced AT Increasing Productivity

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

For millions of Americans, the daily tasks of living and functioning are made more complicated by disabilities. However, with the ever-increasing advancements in technology, many individuals are finding new ways to adapt and improve their quality of life and ability to live independently. Many are now relying on assistive technology (AT) to maintain a livable level of daily functioning. However, though technology advances at a breathtaking rate, those individuals who could benefit most from new improvements and developments in AT are often left in the dust. Many people with disabilities are not functioning at their highest potential because of a lack or failure of their AT. Many people are unable to afford the devices they need or are simply unaware of the beneficial AT available to them.

Defining Function

The term “function” can have various meanings depending on context; the definition of function employed by an occupational therapist may have connotations that differ from those of the everyday usage of the word. In order to be clear on what function means for our project, we have to look at it in the context of our project, and the lives of people with disabilities.

The California Foundation for Independent Living Centers (CFILC) project, Community Research for Assistive Technology (CR4AT), by employing participatory action research, seeks to use an ecological model for interpreting the research results. The ecological model investigates results on three levels: policy, service and individual. Function is the most individual of all the subjects we looked at because it is confined to the individual. There may be policy regarding how low one’s level of functioning can be before being eligible for support, and there may be services that are provided to help one function, but the action of functioning actually happens at the individual level. In the ecological model, one of our focuses is investigating the connection between the policy, service, and individual levels. When looking at services, one looks at the policies that drive the services and the impact on the function of the individual. Environments, for example, can impact how individuals can function.

Individual models of disability, in the past, have been associated with a tragedy or medical model of disability (Barnes, Mercer and Shakespeare, 1999: 21). In contrast, the social model says that disability is an outcome of an oppressive relationship between people with impairments and the rest of society (Barnes, Mercer and Shakespeare, 1999:27-28). At the societal level the organizations of systems of health, education, and social welfare affect how people with disabilities can participate in their communities. So when we are looking at functioning we are looking at the micro level of individuals' functioning but are aware of the larger social context.

We examined through the focus groups the relationship between the daily functioning of individuals with disabilities and their use of AT. For the purposes of this investigation, when we examined "function," we addressed those elements of daily living that comprise the bare essentials. Our goal was to better understand how AT helps people with disabilities to physically, socially, or cognitively function in their world. We wanted to discover how consumers use AT to get from one place to another, to communicate, to use their arms or legs with more ease, to see or listen better, or to enhance their cognitive functioning abilities.

Function can be a measurable concept: strength, agility, level of hearing, vision, or speaking ability are all areas that can be tested and measured. An audiology exam, a vision exam, strength exam, neurology exam, or regular physician's examination can all assess function, and they usually do not assess function in a context specific to someone's life, such as parenting, independent living, or employment.

We limited the definition of "function" to physical movement, physical ability, and cognitive skills, the mechanics of daily functioning aided by AT. Function, however, remains closely tied to each of the other five thematic issues being investigated by this research effort, such as independent living, health, and funding. All of the six separate areas under investigation together comprise the complete picture of current circumstances faced by consumers. In focusing on function, we illuminate one area of the issue, but also shed light on those topics inextricably related to it, creating a complete picture of the successes and failings of the current AT system in all areas, not merely function alone.

How Does AT Help People Function?

The definition employed by the Tech Act reflects the diversity of devices and

objects that can be used as AT—anything from expensive “high-tech” aids such as voice-activated software, to “low-tech” devices like grab bars or canes, to objects modified from their original use to take on a new function in assisting a person with a disability, such as a shopping cart used by one respondent like a walker for extra support in the grocery store. Focus group participants told us they used a broad spectrum of AT, some employing very simple devices, others requiring highly specialized and technologically advanced AT to be able to function daily.

Assistive technology has helped individuals with disabilities achieve and maintain full access and function in their homes and community. 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. Activities such as mobility, reading, cooking and cleaning, personal care activities such as bathing and using the toilet, employment, and education were all affected functionally through the use of AT. One focus group participant noted:

“I use a number of different AT devices. I use reading glasses to be able to read and I also use a modified vehicle van to get around with a lift. I use a power wheelchair. I use handless phones at work plus a modernized computer. I also use a sliding board to transfer. So, I utilize a different type of AT to be able to meet my daily living needs.... I have enough things to where they keep me going everyday.”

Many of the AT items used to increase function aided mobility. Being able to move about in and outside of the house is a crucial element of functional independence, enabling consumers to gain vital access to their communities. Focus group participants frequently reported using manual or electric wheelchairs, walkers, scooters, canes and crutches, as well as modified vehicles for transport over longer distances. Braces for various parts of the body were also mentioned as mobility-related AT. Grab bars, slip-proof mats, and other added safety elements in bathrooms and showers helped individuals move about the home, enabling them to live independently and take care of themselves more easily and safely. Forms of AT, like grabbers, reachers, and one-handed can openers, were also used to improve agility and perform household or job-related tasks.

Communication appeared as a functional necessity that was aided by many types of AT. Types of AT that facilitate communication are often indispensable for persons with disabilities. Communication devices can help consumers overcome isolation and interact in their communities, gain or maintain employment, or even relate their basic needs to caregivers. Computers, with adapted software such as voice-recognition software or a screen reader, or adapted hardware like an adaptable mouse or keyboard, or a screen enlarger, were commonly cited AT for persons with a wide variety of disabilities. One respondent mentioned his artificial larynx device that aided him in communicating verbally. Visually impaired individuals used a variety of AT to help them communicate at work and socially; screen readers for use with computers, magnifiers, closed circuit television (CCTV), portable Braille note-taking devices, are examples. Hearing-impaired individuals often use text telephone services. Many hearing impaired persons also found e-mail an ideal method of communication because it is more widely accepted among hearing individuals. Numerous participants reported relying upon hearing aids, one of the most widely used forms of electronic AT, to aid communication:

“I can’t really function without my hearing aids. It’s something that I have to use every day.”

Many consumers revealed that an adaptive and creative spirit can make life easier; modifying devices to meet one’s special needs, using common items in new or different ways, or even merely taking advantage of technology commonly available in society fulfilled individuals’ AT needs. For example, one participant related how a combination of common pieces of technology and specialized AT can benefit cognitive functioning ability:

“I had a stroke...and one of the things that has been a great help to me is my cell phone, which also has very easy-to-set alarms installed which reminds me of various times. I have had an electronic organizer with a keyboard inside of it. I also use a visual recorder to dictate into.”

The functional value of AT devices directly relates to the productivity of persons in employment and school, allowing them to function effectively in the community and perform well.

“...When I do the counseling, a lot of people don’t like to be recorded in sessions, but I can’t really take great notes because of

my hands so I explain to them that I am going to tape it, just so that after I can take notes, then I will throw away the tape or erase it; and that also helps me having my little tape recorder, which are really good for me for note taking. I would forget what we talked about, it makes it a whole lot easier.”

The functional value of devices had a direct link to the impact of the respondents' health. Health and safety are key influences on an individual's capacity to function. Persons with disabilities may use a variety of devices to allow them to function more safely, in ways that do not endanger their health and in ways that can actually improve their health. Participants commonly related that without AT, their physical health would dramatically decrease.

“My condition deteriorates very rapidly. If I don't have my cushion, I actually get physical damage.”

Some of the people who had functional needs had things such as a nebulizer, inhalation therapy, and oxygen. These are the kind of things that are very much related to health, and at the same time increase people's function. With the use of devices such as these, people can walk for longer periods of time with the oxygen than without the oxygen, which increases their function in daily life.

Although there were different topics in each focus group, function was an underlying theme in all of them due to its direct relationship to AT use. In each and every focus group conducted, participants relayed the value of AT in maintaining their quality of life and providing a range of functional values. AT decreased fatigue, decreased pain, and provided persons with the ability to perform activities normally out of their range. Many people rely on their AT not only for a better quality of life, but for basic needs. AT has become a crucial element in continuing a normal daily existence for many. When asked about the repercussions of possibly losing his or her AT, one respondent replied:

“Well, I would be mad; I wouldn't be in trouble, I would be dead. The impact would be very tremendous.”

Other participants responded with a chorus of the possible catastrophes if they were to be without AT devices:

“I couldn't see.”

“I couldn’t read, see things.”

For some people, vision was a key to functioning.

“You’d be stuck in your house.”

“My AT is my walker and if I didn’t have my walker I wouldn’t be able to go anywhere. I can’t walk; my walker is number one in my life.”

“I couldn’t do anything.”

For others, mobility provides the ability to get things done.

Universally, the focus groups confirmed the value, and sometimes utter necessity of AT in improving the participants’ ability to function in life. However, though grateful for the help that AT renders, many respondents cited the need for improvements in AT design.

“They need to have the engineers take a coffee break and listen to us.”

Their experiences with poorly designed AT led many to wonder if their needs as consumers had been left out of the product design process. Though the value of AT is virtually indisputable, certain elements in the design of AT devices contribute significantly to their ability to provide for the needs of the consumer.

Portability for mobility devices was mentioned several times throughout the focus groups. The inability to transport mobility devices such as a wheelchair without assistance affected the functional value of the devices. One participant complained that while her motorized wheelchair helped her get around great, it was too heavy a unit to easily transport in a car, making it difficult for her to leave the house. The inherent portability of smaller devices, such as a Braille note taker, was mentioned as a great asset.

Certain types of AT were preferred over others for their ease of use. The most successful AT devices, those that rendered the user with the most functional value, were items that were simple, required little maintenance, and decreased pain. Cost was also an important factor. Many items reported were homemade

or everyday items altered to become AT. This consumer related how she was able to fulfill the demands of parenting by modifying a conventional device to ease the pain and difficulty of the task:

“I had a regular baby crib and a friend of mine took the front railing off of the bed and put a track and cut the front railing in half so that the railing could slide to the side; that way I could put the baby in and get her out without putting a lot of stress on my back, and that was a tremendous help to me. I don’t have any more pain now. It is like a sliding glass door.”

Function and Funding: Getting What We Need

Even after a person with a disability identifies the need for AT, the issue of paying for it becomes, for some, a barrier keeping them from a higher standard of independent living.

There are as many ways to pay for AT as there are price ranges of AT. Some individuals elect to or have no other choice but to pay for the needed devices themselves. Others find financial support through veteran’s benefits, the California Department of Rehabilitation, Medicare or Medi-Cal, or health maintenance organizations (HMOs). Donated or borrowed AT is a reality for some, and such items come at little or no cost. Self-payment was most often practiced for smaller, “low-tech” devices, whereas individuals often needed financial assistance to obtain more expensive items. Tax incentives from the government made self-funding of AT more feasible.

“...I use it for a tax write off—any equipment that you need because you are deaf can be written off.”

Some systems that aid in funding AT remain inadequate. Some consumers were able to receive assistance for only a fraction of the AT they required, complained of being uninformed about their funding options, and stated they were confused by the overly-complex system. Consumers admitted feeling frustrated with the current system in place to acquire their AT, but have no alternative.

“I don’t know how they really think it can work. I’m a pawn there. They take as long as they need, and I just go without. As long as they give me something that I can use.”

Time delays in receiving necessary AT can create a variety of problems for the user—some devices are needed immediately but only for a limited amount of time. Some participants revealed that by the time they actually received their AT, they no longer had a need for it. Others must face a reduction in functional ability while they await their AT, dealing with insufficient AT or none at all.

However, despite delays or problems, many persons with disabilities receive significant financial help and are able to obtain the AT they require. Participants stressed that self-advocacy was important; one must be well informed and be assertive and persistent in voicing one's needs. This is a system, and it best serves those who know it.

AT Problems

Consumers face an assortment of barriers that prevent them from reaping the maximum benefits from the AT they use. Individually, some consumers reported difficulties due to the lack of compatibility between the devices they received. Some items were uncomfortable, or poorly suited the consumer's individual needs. The mismatch of AT devices caused discomfort, increased the effect of pain, and sometimes risked safety. However, people often endured inadequate AT because of the lack of a viable alternative. Consumers shared that they would prefer a greater choice in selecting appropriate AT that fit better with their needs.

“They didn’t even measure me. They just got one of the regular standard ones, like from the closet. So the Regional Center paid a vendor to get me the chair and they delivered it. And it has foot pedals and it has the level back. I deal with it. If I’m in there for a long time, I’m not very comfortable, but I’m just lucky to be able to have a wheelchair that holds me up.”

When devices were not easy to use or malfunctioned, respondents commented on the resulting frustration and confusion when trying to use their devices.

“Every time I try to use my Zoom Text, it goes all wacky; I’ll be reading something and then I’m like, ‘Where did it go?’ It will go to the top of the page and start all over again... it goes crazy.”

The functional value of hearing aids, one of the most commonly utilized forms of AT, was discussed when respondents relayed stories regarding the compatibility of their devices. For many, hearing aids were not comfortable to wear and caused further pain such as headaches. In addition, it was found that hearing aids are not compatible with all environments and therefore rendered unusable in certain situations, such as those with excessive background noise. Some consumers voiced the need for greater attention to be paid to their needs and preferences by those working to provide them with AT.

“I have a hearing aid that I don’t use because my glasses are so thick and when I wear them with the hearing aid it hurts my ear. I told my doctor that I need the inner ear hearing aid and they told me that the outside one would be better for me, so I just don’t wear it. How are they going to tell me? I know what is best for me and what is more comfortable. I have a little ear—I can’t hold the hearing aid up on it!”

As seen in the above comment, some problems become so significant that the user eventually ceases to use the device at all. We found that people abandoned their AT for many different reasons. Many find that they no longer need the same types of AT because their disability or condition has changed. However, some respondents received their AT but never used it due to a poor match, such as items that fit improperly or were uncomfortable, or because the AT was not easy to use.

Many persons received their AT with no professional training on proper usage. This can result in abandonment of AT and a waste of funds, or situations in which consumers are under-utilizing the AT and not realizing their full functional potential. One participant, when asked about the training or instruction received with the AT device, replied:

“None really, I still don’t totally know how to use my AT.”

In other cases examined, aesthetics or the stigma attached to using AT hindered them from using the AT prescribed.

“Some people just don’t want the rest of the world to know that they can’t see, hear, etc. So they just don’t use their devices.”

“I have a wheelchair, but when it was given to me I was determined that I was going to walk; so right after I got it I put it in the back of my closet; I didn’t want to be confined to that chair.”

Repairing AT

“You are in a situation where you get up everyday hoping that your chair comes on or your lift goes down and you just hope all this stuff for daily living will work.”

Persons with disabilities often come to rely heavily upon their AT. Unfortunately, consumers reported breakdowns or failure of their AT. Consumers discovered firsthand the difficulty of coping without it, and of trying to repair or replace the AT. Respondents encountered numerous obstacles when devices broke down and needed to be repaired or replaced. The unavailability of back up AT or loaner AT, the amount of time it takes to repair or replace items, all proved to have a negative impact on the daily functioning of persons with disabilities.

For those who have back-up AT or received a loaned device from an acquaintance or organization, the effect was not as detrimental as those who had nothing to replace the AT that had broken down and was no longer usable. However, decreased functioning still occurred when the regular AT was not available for use.

“I have two wheelchairs. Thank God I kept my manual chair, so when this one breaks down I take that one down. I am not as able as I am in this one, but it’s something.”

The amount of time involved in repairing or replacing AT results in decreased function and independence. Due to the amount of time involved in navigating the funding systems that repair or replace AT devices, respondents claimed that their daily activities were greatly impacted for weeks, if not months.

“When someone’s AT equipment breaks down, it is not like driving to the store and buying a piece. If it is covered under insurance there is a huge lag time from the time it breaks down to the time it is approved by the insurance company to replace it; we can be talking weeks or maybe even a couple of months. Even if you know in advance that you are going to need tires for your wheelchair...

you are still looking at 4 to 5 weeks on the short side.”

Not all repairs on AT prove problematic or lengthy. Several respondents commented that when AT broke down, they received a quick response from their local vendors who made the needed repairs in a timely manner. For these persons, there was often a technical support number associated with their devices that allowed them to connect with the appropriate persons quickly.

“Whenever something is wrong with it or I need a new one I just call up the representative and they would send someone out and they would fit me to see if certain ones would fit me, but they always take care of any problems that I have with equipment.”

Quicker repairs and replacements resulted in less lifestyle change and less loss of functional ability. Consumers whose needs were addressed sooner spent less time coping with the loss of AT, more time living at the standard to which they had become accustomed with their AT. However, for those situations in which repairs involve a lengthy process, the result can amount to more than mere inconvenience. An individual’s lifestyle may be dramatically disrupted when AT is not available or not operational. Without AT, many are unable to move about the house or to and from work, suffer a loss in communicational abilities, and in some cases, lose their ability to live independently until their AT is repaired or replaced.

“This guy had his own business and he was supposed to take my wheelchair and get it fixed, and he had it for like 6 months. He tried to charge Medi-Cal for batteries that I didn’t even ask for. We kept calling and he never returned phone calls. And I had a job and some people from the Board helped me and they had an investigation. Meanwhile, while this was going on, I was in a manual wheelchair and my aides had to stay with me 24 hours a day. So my independence was taken away. I was very frustrated.”

This quote exemplifies the danger in being without AT: one may not be able to function independently, and may suffer a restricted capacity to function. Our concern is that disabled people who are unable to acquire the AT they need to live independently will experience an increased risk of institutionalization, and that within the setting of nursing homes or other care facilities, persons with disabilities will have less access to AT. AT has a key role to play in maintaining functional ability and thus independence in the lives of people with disabilities.

“So they had this investigation and he basically got off free. Meanwhile, the Regional Center said, ‘what do we have to do to get her wheelchair back? We’ll pay you.’ What they did, and this is a big mistake with the Regional Center, they were going to pay him to get my chair back, but my chair was supposed to be in working condition because when it left it was in working condition, it just needed some little repairs. So the guy brought it back and it was in pieces. So [a new vendor] came out and assessed me for a wheelchair and then I finally got it. But it took a half a year of my independence.”

Action Strategies

Function includes hearing, seeing, walking, talking, thinking, moving, lifting, carrying, all of those things that are a part of our regular life which have an impact on the things that we are able to do in terms of participating in our world. At the individual level, we experience differences in functional ability. Some of those include things like fatigue, pain, and difference in feeling or sometimes called difference in sensation, confusion, weakness, paralysis, as well as difficulty in maintaining or endurance.

Referring back to the ecological model, we can classify these problems as existing at the individual level; then at the service level these particular areas of functioning are supported in the community in different ways. AT is provided or referred by people such as occupational therapists, physiotherapists or even AT specialists, and doctors. Doctors can write prescriptions for a shower chair or grab bars in the bathroom, and often they know very basic types of AT, but don’t know the more sophisticated types of AT. The specialists, like occupational therapists, often know of a better and wider range of equipment. An occupational therapist focuses on getting people back to the pre-disability state. Someone with a disability from birth will often have already had quite a bit of evaluation and know what pieces of equipment are needed for use.

One of the areas we’ve isolated as needing improvement on the service level for function is having more consumer input on the evaluation of disability function. Our goal is to increase the extent to which consumers have a say in what gets assessed and how it gets assessed, particularly in how important

things are; what might seem unimportant to a non-disabled physiotherapist might be quite important to the disabled person.

The policy level is where the organizations that provide the services of physiotherapy and occupational therapy and doctors get their funding and their mandates. If HMOs, Medi-Cal, or any of the funding mechanisms didn't specify in writing that AT is a benefit for which consumers are eligible for funding, then people with disabilities would not be able to go and be assessed and referred. Funding also comes in because if the policy does not provide funding for the AT, then basically the evaluation is only an evaluation, and does not follow through with the needed AT. Again, this includes low-tech devices such as canes and walkers. A lot of the people we spoke to in the interviews and focus groups told us that a lot of the issues were not about the electronic, high-tech AT, such as \$7,000 computers, they were about things like bath chairs and bath rails, and that people with disabilities often need very basic things that are not being provided. We want to look at the policy level in terms of what is fundable, what is in the books as being fundable, and how the policies are implemented at the level of the HMO or insurance; we want to see a situation where the physiotherapist or occupational therapist and doctor can provide referrals and recommendations that will actually get funded, instead of providing an evaluation that does not actually result in getting the equipment for use.

From the results of our focus groups, we can witness the many benefits AT has had in our participants' ability to function. Individuals were better enabled to work, parent, interact in the community, remain healthy and pain-free, be safe, and live independently with their AT.

We can also recognize that some elements must change before every individual can embrace the opportunity to function at an equal level. In our continuing goal to enable all persons with disabilities to pursue the independent lifestyle to which they have a right, the CR4AT project on behalf of the CFILC will apply what we have learned to engage in more informed and effective advocacy that directly reflects the needs of the community we represent.

Is all this worth it? Does AT really improve lives? In the words of one participant:

“Immensely. And you don’t know that until you actually have it then you think, ‘WOW, what a difference. I can hear, I can function now’.”

Through the Looking Glass

Meso AT Success Story

In conducting our focus groups we met with several parents with disabilities who used a range of technology both for parenting and other independent living functions. The organization that provided most of them with assessment and equipment is a nationally recognized, San Francisco Bay Area organization. This story discusses how the organization provides services that support the technology needs of parents and children with disabilities.

From the website: <http://www.lookingglass.org/>

Through the Looking Glass (TLG) is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability or medical issue. TLG is a disability and deaf community-based nonprofit organization, which emerged from the independent living movement, and was founded in 1982 in Berkeley, California. Their mission is *“To create, demonstrate and encourage non-pathological and empowering resources and model early intervention services for families with disability issues in parent or child which integrate expertise derived from personal disability experience and disability culture.”*

Through the Looking Glass emphasizes a life cycle approach which integrates a number of disability, cultural and professional perspectives. The dialogue between non-peers, people with disabilities, parents of children with disabilities, siblings, spouses and adult children of parents with disabilities or deaf parents is sometimes hard and always fertile. TLG is a celebration of diverse perspectives and a demonstration that these perspectives can be bridged and that bridging them can produce particularly effective, empathetic and respectful family intervention as well as innovative approaches to research, training and resource development.

TLG’s staff includes psychologists, researchers, occupational and physical therapists, rehabilitation counselors, social workers, marriage, child and family therapists, developmental specialists, and childbirth educators. The staff is diverse culturally and linguistically, and nearly 80% of the 35 staff members are disabled, parents of disabled children, or members of families with disabilities or deafness.

National Resource Center for Parents with Disabilities (NRC)

Since 1998, TLG has been funded by the U.S. Department of Education as the National Resource Center for Parents with Disabilities. This National Resource Center (NRC) targets the 8.4 million parents with disabilities in the U.S. as well as family members and professionals who work with these parents. The NRC provides:

- Information and Referral
- Publications, Videos and Training Modules
- Technical Assistance and Consultations
- A national Parent-to-Parent Network of parents with disabilities
- Professional Trainings and Workshops
- A International Newsletter
- A national Library and Clearinghouse of Resources
- A Website & Bulletin Boards

The information and resources of the NRC cover diverse parents with disabilities including Deaf parents, blind parents, and parents with physical, intellectual or psychiatric disabilities. In addition to general information on parenting with a disability, the NRC is particularly focused on custody, adoption, adaptive baby care/parenting equipment, and pregnancy and birthing. Most of the NRC information and resources are available free-of-charge.

Adaptive Equipment

In the San Francisco Bay Area TLG services include adaptive baby care/parenting equipment evaluation and provision for parents, expectant parents or parenting grandparents with disabilities or deafness.

Parents are able to work with the staff at TLG to determine which equipment will work best for them. The equipment can include adapted equipment or mainstream equipment that is used for adaptive purposes. Many of the baby care adaptations were designed and developed by TLG staff, under the auspices of NIDRR-funded research projects. There are ways to hold a child, fixed seating on a wheelchair or walker, side opening baby cribs, adaptive devices to help blind parents measure medication, and light alerts to tell deaf parents when babies are crying. Parents are able to participate in support groups where they meet other parents and learn together about various ways to cope with having a baby or child. There are books and reports available for

parents to look through, videotapes illustrating adaptations, as well as staff to talk to. Most of TLG's services are provided through home visiting. Parents can also receive home-based psychotherapy or family support, e.g. when there is a new or worsened disability or other family stresses.

A TLG early intervention project for parents with intellectual disabilities includes the provision of appropriate cognitive adaptations in parenting services, as well as a support and empowerment group adapted to the disability needs of participating mothers.

TLG's expertise regarding parenting adaptations is channeled into its publications, training and technical assistance, available nationally and internationally.

For instance, TLG has prioritized training more occupational therapists so more parents with disabilities can locate assistance with baby care equipment all over the U.S. Many graduate occupational therapy training programs have purchased TLG's curriculum regarding baby care equipment. A current NIDRR-funded project is developing an evaluation tool for guiding occupational therapists to meet the baby care adaptation needs of parents with physical disabilities.

TLG also focuses on training professionals in family courts and child protection systems so they understand the role of appropriate disability and parenting adaptations in evaluation and intervention; the goal is to promote appropriate and non-discriminatory practice with parents with disabilities, deaf parents and their children.

The awareness about parenting adaptations and their role in family life also is incorporated in TLG's home-based early intervention to infants and children with disabilities and their families. For instance, many adapted toys are useful both for disabled children and for disabled parents. A number of parents of disabled children have found that TLG's work with disabled parents offers a hopeful "window on the future" for their children.

This organization has funding from federal, state and county sources, foundations and donations, and usually does not charge for its services.

This is an example of a disability-positive, non-pathological approach to assistive technology and parenting.

Healthier Bodies

Access to Services and Exercise

by Eleanor Higgins, Ph.D. and Tanis Doe, Ph.D.

According to Kailes, getting the most out of healthcare services requires people with disabilities to manage their own healthcare (Special Report: Minding Your Health). The Americans with Disabilities Act appears to guarantee access to health care for all, including basic medical care, health information and education, and health-promoting activities, but it continues to be denied to many people with disabilities. Any number of obstacles can block a disabled person's access to health services and activities, including financial hardship, insurance coverage limits, lack of sensitivity and training on the part health practitioners and difficulties with physical access to facilities.

What AT Is Used for Health Purposes?

When asked what types of AT consumers with disabilities used in health settings and to gain access to health settings, consumers reported a wide variety of mobility-related technologies from canes to power wheelchairs, adapted vehicles, medical information produced in a variety of formats such as Braille, enlarged text, screen-readable electronic versions, translated material, hearing aids and TTY's, a variety of hand-held communication devices, public and contracted transportation services, and modified physical environmental aids such as ramps and automatic doors. Once in a health facility, many reported using AT in the form of adapted medical equipment such as lifts, adjustable exam tables, x-ray and mammogram equipment, and specialized blood pressure and other testing devices. Respondents also used various AT to perform routine health care tasks such as medication reminders and alarms, talking watches, talking blood sugar meters, magnification equipment and eye glasses. AT devices were also used to obtain and prepare food to enhance nutritional status such as scooters and other mobility devices, reachers, grab bars, adapted jar and can openers and the like. Finally, a variety of technologies were employed to increase the quality and quantity of physical exercise such as adapted exercise equipment, braces, straps, orthopedic shoes, and various pieces of sports equipment that emit sound.

In addition to persons with disabilities, other stakeholders have recognized the

complexity of health care barriers that involve the relationship of the disabled individual to the disabling environment. For example, Scherer (1996), an engineer in the field of technology and disability, suggests, "Individual and environmental deficit modification need to go hand in hand." The CR4AT project used an ecological approach to community research and technology, which holds that individuals with disabilities are part of an ongoing system of action and reaction, in which they are both actors and acted upon. The ecological perspective contends that the social environment is not only shaped by society but also has an impact on members of that society. Individuals within communities are influenced by the community, but also participate in its creation and evolution. Using an interactive systems model, the ecological approach requires that issues be investigated at the individual, institutional and environmental levels.

Why Is AT Important?

Our participants reported that their AT directly reduced pain and fatigue, as well as helped them recover from and prevent further injury.

"When I am in an environment where I can't use my power chair [traveling] my health declines really quickly. My pain level increases dramatically and my exhaustion increases dramatically. My ability to take care of myself decreases very rapidly."

Physical disabilities can cause pain-related restrictions that could be reduced through the use of technology. Pain can be a significant cause of health service use if it is not properly controlled. With the right equipment, some forms of pain can be prevented as well as relieved.

"[My AT] has actually taken the pressure off my jaw and the wear and tear off my joints and allows me to type pain-free."

"The impact on my health going from a push chair to power chair is it has kept me from going into surgery on my two shoulders."

These were some examples of how health and AT interact in addition to the AT that provides consumers the mobility to utilize various health facilities.

"If my chair was broken and I just had the crutches I couldn't walk"

the distance that I needed to [so] I would have to cancel the appointment.”

AT allowed participants to prepare their own food, which led to improved nutrition, and increased participants' ability to get more and healthier exercise.

“I got a scooter used for the grocery store. If you can't get the food you can't cook it yourself and have to eat fast food. Not very healthy.”

“My back brace helps me because all I was doing was sitting at home getting fat. I couldn't move around and that was kind of destructive. I couldn't get any exercise.”

AT also improved consumers' mental and emotional health. AT helped them to participate in mentally stimulating activities, develop better relationships, and increase self-sufficiency, all of which improved their feeling of well-being and general mental health.

“So many older people, as they lose their hearing, are frustrated and stressed out because they can't communicate...something as small as a hearing aid can change a person's life.”

Many participants mentioned the impact AT had had on their mental and emotional health. Improved function afforded by AT allowed them to participate in mentally stimulating activities, get out to be with friends, and develop better relationships within the family, which had a positive effect on their mental and emotional health.

“You lost [your AT] then you got it back so that has increased your confidence and you have a good feeling about yourself and you are feeling whole again.”

AT also allowed participants to be employed and thus qualify for private health insurance paid for by their employers. This permitted access to better and more frequent health care services, as well as offering funding for a portion of their AT needs. Finally, by undergoing the process of obtaining AT, difficult as it may have been, many participants believed they benefited from the experience by learning the skills of advocating for themselves, which they

believed improved self-confidence, independence and general mental health.

How Do People Get AT?

Once AT is prescribed, which can be a lengthy process itself, most participants obtained their expensive items from either private or public insurance sources, or other public agencies such as the Department of Rehabilitation if the AT is needed for employment. The process of obtaining public funding can create exceptionally long waits as well.

“When the doctor is recommending it you need it at that time. What if you don’t need it 3 months later when you actually get it?”

“I got a computer, but I had to fight for 3 years for it.”

“It was 6 months between my doctor [prescribing it] and the company that supplied the chair.”

The length of time it took for people to get urgently needed equipment was disappointing. We were surprised to find that a lot more people than we expected were paying for their low-cost AT items themselves.

“Many of the devices that I have I purchased them myself because I had enough money to but them without going through my health insurance company.”

“I went over there and Medi-Cal didn’t want to pay, so I had to get the money to buy it. It was about 4 weeks.”

Success Stories

As mentioned earlier, we were happy to learn that many people’s health was enriched by AT.

“Once by accident I asked for an accessible table and they gave me one of the “Sandy Welner’ tables at my HMO and it’s an examination table that is height adjustable...It was the best physical exam I have ever had in my life. It was fabulous to be able to feel comfortable about getting on and off the exam table. It was the first time I didn’t feel scared.”

“Having a manual chair is very important to me. It keeps my heart strong and helps me exercise.”

Not-So-Success Stories

Participants felt that changes in the health care system would further improve their access to services and AT. Health care personnel need better training on how to meet the needs of persons with disabilities.

“I went for a bone scan...and they dropped me when I was getting transferred onto the table...and said ‘you didn’t tell me she couldn’t bear weight on her legs.’ Why don’t they train people? They should give them training.”

“When they wear a mask...I can’t read lips. A long time ago they had me tied down by the wrists. They thought I was crazy. The nurse finally asked, ‘Are you deaf?’ I said yes.”

Participants also maintained that medical professionals require training on currently available assistive technology:

“Doctors are clueless, so I usually go in with my research all done and just tell them what I need.”

Also mentioned was the need for training in being sensitive to prejudices that can develop concerning their status as disabled people, and or members of ethnic and age-related minorities.

“I feel that the doctors don’t care for old people because they feel that our lives are over anyway. Sometimes you feel like you are wasting their time.”

Strategies for Improvement

Participants would like to see a proliferation of accessible medical facilities and equipment.

“Neither of us [respondent and daughter] has been weighed in years.”

“An x-ray room can be a nightmare for a person with a disability.”

Finally, since many disabled people subsist on a severely limited income, they would like to see the health care system develop a culture in which institutional decision makers hold the goal of improving the provision of services and equipment in a timely manner to persons with disabilities, as opposed to containing costs.

“They denied me [a power chair] because I had mobility in my arms, but I have a bad back so I couldn’t push very far.”

“Medi-Cal wouldn’t pay because I have Medicare, and Medicare wouldn’t pay because I volunteer.”

“When the doctor is recommending it, you need it at that time. What if you don’t need it 3 months later when you actually get it?”

“It was 6 months between my doctor [prescribing it] and the company that supplied the chair.”

Many believe overall health care costs would eventually decrease in the long run if appropriate AT were provided without lengthy delays.

“[Many people] are frustrated and stressed out because they can’t communicate and that stress in itself causes heart attacks, strokes and mental problems simply because they can’t communicate. If doctors and insurance professionals were enlightened on the fact, the over all costs over a few years would go down.”

Conclusion

Participants used a large variety of AT to enhance their health. It allowed them the mobility to access health care facilities, reduced pain and fatigue, avoid injury and the need for surgery and improved overall mental health. They often obtained funding for their AT from private and public insurance programs and other public agencies. Waits were likely to be lengthy when negotiating public institutions. There was much more self-funding than we expected to see. Participants would like to see a proliferation of accessible medical equipment, and for the health care system to develop a culture in which institutional

decision makers hold the goal of improving the provision services and equipment in a timely manner to persons with disabilities as opposed to containing costs.

Differential Benefits

AT for Underserved Populations

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

Introduction

The Community Research for Assistive Technology (CR4AT) project has been interested in whether people with disabilities experienced differences in AT use and access because of their membership in certain population groups. We identified groups at risk such as aging people, rural residents, and people with some types of disability. Our questions related to how the status of these populations impacted their use of and access to assistive technology (AT). Questions concerning these issues included the following:

- How does AT impact the health and independence of people with a wide variety of disabilities? Is it different depending on the disability?
- What types of AT are helpful in the workplace for persons with a wide variety of disabilities doing a range of jobs?
- How can AT be better harnessed to fulfill the promise of community integration for various disability populations?
- How does age and rural living status impact the access populations have to appropriate technology?

Focus groups were held with members of the following disability populations: blind/low vision, Deaf/hard of hearing, developmental disability, psychiatric disability and speech disability. People with a range of physical disabilities were present in all of the other focus groups but their answers were not isolated for this chapter. Focus groups were also held with people in the aging population and people living in rural areas. Together, the responses from these under-served populations create this report.

Aging Population:

Current statistics also show that the percentage of people with disabilities increases with age and disability takes a heavier toll on the elderly (Administration on Aging, 2002). CR4AT research is proposing that assistive

technologies can improve people's quality of life and could become increasingly more important. Continuous advances in technology are enabling people to redefine themselves and their outlook on life.

Time is especially important for people within this population because of their age. A few people expressed concerns about whether they would ever get their AT devices and AT related-services. Lengthy waiting lists often leave people wondering if they will even be alive by the time they reach the top of the list. One participant shared that although her husband had long-term care insurance, he passed away before he could even take advantage of it. As people within this group age, disability needs may change or worsen.

Rural Population with Disabilities:

Of the 53.3 million rural residents of the United States, 12.5 million have disabilities and 6 million have severe disabilities (Research and Training Center on Disabilities in Rural Communities (RTC Rural), Background Information, Statistics and Demographics). There is limited access to transportation, health services and higher paying jobs (Congressional Rural Caucus, Fast Facts; California State Rural Health Association, 2003). Access to accessible transportation, service providers, local services and more is very limited (RTC Rural, Background Information, Statistics and Demographics). Rural areas of the United States also tend to have higher rates of disability in comparison to more urban areas. In Enders & Seekins (1998), the authors attribute this to dangerous occupations that can result in high rates of injuries, a higher proportion of older Americans in rural areas, limited access to health services and high poverty levels. Health and safety is also put at risk when people are giving no other alternatives. In many cases, public transportation only ran twice a day, once in the morning and again in the evening. As alternatives, consumers set up informal ride-shares or hitchhiked to arrive at their destinations. One participant said:

"I would change the transit. They would pick me up late or way ahead of time and it was just unreal...so I drive myself, but I know that I am going to have to stop because I am legally blind."

There were not many references to successful employment from consumers in this population. This may be because people with disabilities are seen as "an

entity to be serviced,” rather than a population that can benefit from better employment access and job training programs (Enders & Seekins, 1998). Other consumers, fed up with the local system, may move closer to their service provider or to a more urban area. Because of these complications and more, focus group participants want better transportation systems in their communities. Adequate transportation systems could increase access to employment, health care and services in rural communities.

Specific concerns for the rural population included:

- Is the impact of AT on health and independence different depending on the geographic location of persons with disabilities?
- How does information about health and technology get disseminated successfully across a large geographic area?
- Are there barriers to AT that are unique or more difficult for people with disabilities in rural areas?

Blind and Low Vision:

The biggest problems for blind and low vision consumers dealt with computer use. Consumers told many stories of mishaps where two computer software programs did not work well together. Consumers said:

“JAWS has certain shortcut schemes that can interfere with certain windows, they have been rigged like that...”

“I have noticed that Windows 98 has a lot of glitches in it and the magnifier changes the settings on the mouse.”

Sometimes adaptive programs did not work well with the operating software (ie. Microsoft Windows), other times multiple adaptive programs did not work well with each other. In either case, blind and low vision consumers were left frustrated trying to work on tasks with AT that often worked against them.

Developmental Disabilities:

The biggest problem mentioned by participants in this population was access to education. Multiple participants mentioned attempting to enroll in courses only to find them closed.

“My teacher helped me a lot...all of a sudden she says we’re filled up, and we’ll call you, but she never called back.”

“[The school has] a lot of things...tape recorders, like when you want to learn how to drive again; they help you it’s right there. That’s what I want to learn to do again. My doctor gives them papers, but they never take me back in. I’d like to get back in.”

Deaf and Hard-of-Hearing:

Consumers in these focus groups sometimes found themselves missing out on information. Without the access, members of this population were denied information. If a deaf consumer is traveling in an airport and an important announcement is made over the loudspeaker, this consumer is oblivious unless other accommodations are made to ensure he receives the information.

“...on the return trains I had to keep my eyes open, so that I wouldn’t miss my stop and I was very tired.”

“Better communication [is needed] in airports, etc...[for example,] if I could go somewhere and check large screen monitors.”

Some deaf and hard-of-hearing consumers are interested in seeing a better “interface” between them and the hearing community. One participant went into the hospital and could not read the doctors’ lips because they wore masks over their mouths. The consumer suggested developing clear hospital masks.

Psychiatric Disabilities:

For participants in the psychiatric disabilities focus group, access to medical care and insurance coverage is a major concern. While the mental health care needs of most of the participants were currently being taken care of, people are worried about the insurance limitations. Consumers with psychiatric disabilities feel the level of coverage related to psychiatric needs should be comparable to those of other medical needs. Consumers worry about losing their current levels of coverage and care under Medi-cal upon gaining new employment.

“I would change the limit that the insurance company put on how long a psychiatric patient can stay in [the] hospital when it is

needed for them to go. My insurance has 167 days per lifetime; we should have the same health care that the diabetics get.”

Many consumers with psychiatric disabilities would be interested in devices that would remind them to take their medications. Participants reported experiencing various consequences from taking their medications irregularly.

“I was in a psychiatric hospital about six or seven times because without anybody around to help me I would forget to take my meds. I was getting all out of whack. I wasn’t getting suicidal or anything, I was just going crazy. So I would take a cab down there and they would admit me and put me on my meds on a normal basis and then I would feel great and it was time to go home...a week or two later I would be right back in there again and they all began to worry about me, like I was playing some sort of game.”

Consumers also do not place a high level of trust in their mental health care professionals. Some felt their medical providers placed too high an emphasis on drugs and cared less about the consumer’s overall needs.

Speech Disabilities:

“I don’t have the money to spend on these devices.”

“Things should be more affordable...”

Consumers with speech disabilities are very concerned with the cost of AT. For example, augmentative and alternative communication (AAC) devices can cost up thousands of dollars. Some of the more complex setups, which may include computers with communication software, may cost even more. Consumers with speech disabilities access to potentially beneficial communication technology is hindered due to high costs and a lack of information on other funding opportunities.

Use of AT by Under-Served Populations

Everyday items, such as ropes, may not be AT by themselves, but it becomes a piece of AT when it can be used to increase independence or functionality. Similarly, a computer may seem to be a luxury to the public, but for a person without sight or speech, the computer may be an essential tool for living.

Communication and reading may not be “medical” activities but they are fundamental to living in the world.

When participants were questioned about the types of assistive technology they used, there was a range of answers. Within CR4AT focus groups, consumers from each population group mentioned using a variety of different devices. Among deaf and hard-of-hearing consumers, the most popular AT included computers, for Internet, email and instant messaging, TTY/TDDs, hearing aids and personal amplifiers (ie. ®Radio Shack).

Participants with developmental disabilities reported using computers, sometimes with adaptive software such as Dragon Naturally Speaking, wheelchairs (power and manual), large print and CCTVs.

Computers and related hardware and software were popular with blind/low-vision consumers. Widely used software included JAWS and Zoom Text and hardware included large screen monitors. Other devices mentioned by this population included talking books/books on tape and CCTVs.

Participants with speech disabilities reported using tape recorders, cell phones, computers and amplified voice boxes. Consumers with psychiatric disabilities used computers, telephones and radios as assistive technology.

The full scope of this definition was also apparent in the data collected in focus groups with the aging population. The most commonly used technologies were vision and mobility-related; these devices included specialized eyeglasses (i.e. Computer glasses) and talking watches, along with wheelchairs, canes, and handrails/grab bars. Consumers also used technologies such as talking books, personal alarms, assistive listening devices and grabbers/reachers. While aging participants were very happy to share the different types of AT they used, it is possible devices were missed because consumers did not identify them to be AT. This could include remote control devices for lights (i.e. The Clapper) and cooking aids (timers).

Devices used by rural consumers included low-tech and high-tech, purchased and self-developed. Similar to other focus group participants, many rural consumers were computer users. Consumers often used adaptive software, such as JAWS for Windows and Zoom Text Plus, and adaptive hardware, such as track ball mice and wireless keyboards, to make computers more accessible

to them. Other popular items included canes, manual wheelchairs and CCTVs². A few consumers developed their own AT. Examples included innovations such as tying rope from the bed to the bathroom door for low-vision navigation and painting the edge of steps for low-vision navigation and depth perception.

Why is AT Important for Under-served Populations?

Assistive technology is important to the lives of all people with disabilities because it improves access in all areas of life. It is particularly important for people who may be marginalized or face additional barriers. Using AT, many people with disabilities can venture out of their homes to work and participate in community activities. Results from an AARP survey reported people with disabilities aged 50 and older are interested in “[engaging] in ordinary activities that help connect [them] to others and to take care of [themselves] as [they] age, such as keeping in touch with family and friends, doing household chores, and engaging in exercise and physical activity” (Gibson, 2003). The importance of AT in this respect can be seen at all levels of the ecological model: micro, meso and macro.

At the micro level, consumers are able to use their personal or individual devices to gain access. This reflects the benefits of AT at the most basic level: the individual with a disability. In CR4AT focus groups, participants provided numerous examples of the personal benefits of their AT devices. Many consumers used pagers, personal organizers and alarms on watches to ensure they took their medications on schedule. As previously mentioned, computers were a very popular AT device among participants from all the disability types. Using computers, consumers were able to do homework, hold jobs, shop on the Internet and communicate with others by email or Instant Messenger. Assistive technology benefits at the micro level are limited to the individual and do not generally extend to others.

The meso level reflects those benefits that occur because of services that are put into place or changes made to the environment. The number of people who can benefit at this level is higher than the previous micro level. Although action

² CCTVs or Closed Circuit Television – An electronic magnifying aid for people with some useful vision. Printed materials and objects can be placed under a camera and the magnified image is displayed on a television screen or computer monitor. Mostly used for reading, they can also be used for writing and other activities, such as sewing (Visual Impairments, Access Ingenuity Website).

here is not a direct change to the individual, the subsequent outcomes affect the micro level. This includes consumers working with state and private agencies such as the California Department of Rehabilitation (DOR), the Regional Centers, the Braille Institute and the Independent Living Centers (ILCs). Through the services provided here, many consumers are able to obtain their needed AT. Some of the agencies are also in the funding stream, which will be discussed in the next section.

Environmental access is another important aspect of the meso level. Changes made at the environmental level impact more than the individual, they impact the public. Audible traffic signals commonly used by blind people and wheelchair ramps are popular environmental changes in metropolitan areas. Changes are made to the environment that do not interfere with the public at-large, but can give access to all who need it. This is much more cost effective than individual purchases at the micro level, where individual technology must be purchased for each person. At the environmental level, incorporating a wheelchair ramp not only helps people in wheelchairs, but mothers with baby strollers, people using canes and walkers and people pulling luggage on wheels.

The macro level impacts the highest number of people and involves people beyond the disability population. This level includes both policy and society. There are a number of policies that affect the populations used in these focus groups that can be mentioned here. One well-known example includes the Americans with Disabilities Act, which guarantees equal civil rights to people with disabilities and equal access to public places, employment, transportation, government services and telecommunications. Using laws such as this one, public transportation must be accessible. Related to the implementation of laws and programs are the attitudes of policy makers and the public. In order to ensure services and technology is available to people who need it there must be an attitude shift towards meeting the needs of people with disabilities. Programs and services are put into place to make this a reality and individuals use equipment to travel from place to place. These three levels do not exist on their own; they interact. Action at each level is dependent upon actions in another.

How Do People Get AT?

During focus groups, we asked consumers how they got their devices, including who paid for it and its cost, any necessary assessments and any

training on the device. There were a wide range of answers relating to the acquisition of AT. Similar to other people in this research, these participants received much of their initial information about obtaining needed AT from their physicians. Medical practitioners provided referral information to other organizations, such as the Braille Institute, or wrote prescriptions so consumers could use their health insurance to obtain equipment. Their health insurance provider accepted the recommendation of the physician and filled the prescription.

Many of the consumers from these under-served populations were successfully able to get their AT with this method. Consumers used medical insurance plans to cover wheelchairs, hearing aids, and contact lenses. A few consumers cited good relationships with their medical providers and insurance companies as reasons behind their success. Other consumers however were not as successful. A doctor may not see the importance of AT and stress medications instead. Consumers also encountered insurance companies that refused to cover AT costs.

Consumers from the Aging, Deaf/Hard-of-Hearing, Blind/Low-Vision, and the Developmental Disabilities focus groups reported receiving funding from the California Department of Rehabilitation (DOR). A variety of equipment was funding through this service, including hearing aids, CCTVs, wheelchairs (both power and manual), and computers, including hardware and software. Satisfaction with this funding stream varied. Some consumers were completely satisfied with their experiences. They received their equipment from DOR in a reasonable amount of time and were happy with it. Unfortunately, not all consumers were as pleased. In a Deaf/Hard-of-Hearing focus group, one consumer waited five months to receive AT. Other consumers were not satisfied with the level of service and felt they were not receiving the best benefits possible.

We were surprised to learn how many people and their family members were paying for AT devices themselves. Sometimes consumers were unaware that funding sources were available to help them purchase their devices. Participants were also unwilling to wade through the “red tape” and long waits for their devices. In either case, money was paid out-of-pocket and ranged up to \$3000. Consumers paid out-of-pocket for smaller items like talking watches and hand magnifiers, as they were seen as more affordable. To purchase their

devices, consumers went to retailers, such as Radio Shack, to purchase some of their smaller items. This included such AT as personal amplifiers for hard-of-hearing consumers. Other consumers used mail order catalogs and the Internet to purchase AT. In the case of one consumer, this was the easiest method to purchase devices because there was no retail store in the area. Some people opted to self-purchase items off the shelf because they felt the more expensive devices was not worth the cost, as in the case of a consumer who purchased assistive listening devices from Radio Shack rather than a hearing aid. As the needed equipment increased in cost, it became less attainable, and more consumers turned to government agencies and health insurance for financial assistance in acquiring their devices.

In addition to these more commonly used funding sources, consumers also obtained devices through community programs and organizations and private companies and manufacturers. Through the community programs and organizations, consumers were able to receive information and referral to manufacturers and other providers of assistive technology. Organizations also provided free or donated equipment to consumers or helped to offset the cost of equipment.

A few rural participants mentioned inheriting their AT; examples included wheelchairs and walkers. Family members, friends or acquaintances no longer needed devices and passed them along. While there may not have been choice or formal assessments with these devices, the consumers reported satisfaction with the affordability of the device and the devices itself. Concerns here might be for the suitability or compatibility of a device not properly fitted.

Other funding streams were utilized but were sometimes particular to certain populations. A few participants of the developmental disabilities and speech disabilities focus groups received funding through the school system. We were not sure if this meant the adult education system, colleges or obtaining devices while still in high school. For some, acquiring their needed devices was a struggle and students were not always able to keep their equipment upon graduation or promotion. Participants in focus groups for this report rarely mentioned employer funding.

Success Stories

AT allowed many people to experience life beyond the four walls of their homes. For some, this included simply riding the bus or walking around town.

One consumer with a developmental disability shared the following:

“I go out, I get out of the house and I go around. I have friends and I go hang out with my friends. Like I go to the market and there are the security guards over there and I go play and talk with them, joke with them. [They’ve] known me a long time now.”

An aging consumer with a visual disability used a monocular to enhance her family life.

“People that are sighted have no idea what it takes, it is a lovely little machine and I did find a use for it, my granddaughter does ballet and I have discovered that I can take it to her recitals and get the stage all lines in it and I can see the kids...”

Another participant initially experienced problems while trying to use a new AT device. After asking a neighbor for assistance, the participant attempted to return the device because they did not know how to use it. The AT provider then offered training to acquaint the consumer with the new device.

“So I took [the device] back and had one of the people who worked there come and show me how to use it. I got help for a month learning how to use different devices and she had a lot of patience.”

A deaf participant was able to gain employment as a freelance writer with a newspaper. Using the computer, this consumer was able to telecommute to work.

“...I have never met the people at the newspaper and I have no idea who they are but because of the computer I am able to still be a writer and have a lot of fun with it.”

At a community level, consumers shared how the incorporation of universal design features assisted in their daily lives. With community accessibility, all community members are able to benefit. People with mobility disabilities are able to navigate the supermarkets and shops because there is room to accommodate them within the aisles. At the movie theater, hard-of-hearing consumers can enjoy featured movies with the rest of the community by using

devices provided by the theater. These types of considerations can have positive consequences for a large number of people within the community. Changes to the environment and access to public spaces were fought for by people with disabilities and much of the current access is a result of their efforts (Shapiro, 1994).

Not-So-Successful Stories

Losing access to AT can be a catastrophe. As previously discussed, AT impacts all areas of life. When it suddenly becomes unavailable, adjustments must be made to do without it. Being restricted to a bed can be emotionally devastating when one is used to using a wheelchair.

“I don’t think people know that it is psychologically hard to not have a chair when you have always depended on a chair. It changes my whole condition and I get very depressed. I have been without my chair for a couple of days; my entire life I have been in a chair. Being down for that time for me is very hard because I’m grounded because I can’t walk, and this can go on for a couple weeks at a time and I have a condition that is very severe so for me it is a very big deal.”

As explained by this consumer, losing the benefit of needed AT devices is not to be taken lightly. Without his or her electric wheelchair, this consumer was not able to do all of the things she or he needs or wants to do. This could be going outside and enjoying the park, but it can also mean going to work, grocery shopping and preparing the night’s meal. All of these daily activities are affected by the removal of a consumer’s AT.

Unfortunately the path to access and participation was not always smooth and simple. Sometimes consumers received devices, but did not get adequate training on how to use them.

“I tried to teach myself how to work [the computer system with adaptive hardware and software]. It took 6 weeks for it to physically get going.”

Blind consumers reported receiving devices such as JAWS for employment or personal use and then not receiving any training on how to use the equipment.

Sometimes the negative experience had to do with an aspect of the AT device itself. People were unable to experience the benefits of the AT because it did not work well for them. Commonly cited problems with equipment included size and lack in ease of use. One participant with diabetes explained he could not use his diabetes-related equipment because of it was too small.

“ I have tried to learn how to use [the test strip] but it is too small...I couldn't see the fluid inside and you have to measure that stuff, so that didn't work.”

In other cases, devices did not perform up to par. For example, Deaf consumers in one focus group were not completely satisfied with the captioning provided on the television.

“Sometimes the stations will have bad closed captioning. Sometimes they don't have any, and they are supposed to, and finally they'll show up. I don't know if it's the station, it's really hard to tell. I would say 75% of the time, it's pretty good...25% of the time it's got mistakes.”

Captioning is now being used outside of television. Schools are using it to communicate to students and court rooms use it for Deaf lawyers or witnesses. The technology has improved but the service of typing/transcription provided by the captionist needs to reach the same high standard.

Why Do People Stop Using AT?

Many times the problem was with the device itself. Consumers reported acquired devices did not work well enough or did not work at all. Sometimes it appeared a proper assessment was not done, resulting in a device that did not fit the consumer. This affected its usefulness. It was not the right size, use of the device required the assistance of a second person (besides the user). These are examples of some of the problems experienced by consumers.

“...I have a pair of one-size-fits-all dark wrap-around glasses and I have a small frame and bones, so of course these big glasses are not fitting on my face, so there is no way they can be adjusted to fit me.”

“...Since our house hadn't been modified for a wheelchair, it was

difficult finding one narrow enough to go through doors, particularly in the bathroom.”

The most common reason why people stopped using AT was because it malfunctioned. Unless the consumer has a back-up device, when AT breaks, all of the access disappears. When wheelchairs break, consumers can suddenly be forced to remain in their homes rather than out participating in society. One consumer with shared that without his AT, he would just watch television all day. Many deaf and hard-of-hearing consumers stopped using their hearing aids because of feedback problems. Hearing aids were squealing, creating excess background noise and interfering with the use of other technology equipment, such as cell phones. The response for some members of this population was to wear one hearing aid or none at all.

Some people were no longer able to use their AT because of problems with batteries for their electronic AT devices. One problem was batteries for these devices were too expensive. People could not afford to continually use their device because they could not afford the batteries. One participant began storing her battery-powered magnifying glass in the drawer because continually replacing the batteries and the light bulb got too expensive. Many in this population were not able to utilize their devices because the batteries had died and they did not know how to change them. This was a barrier for a number of various devices, including a talking thermometer. When the initial batteries were good, the device was used regularly, but once those were expended the device was useless. This was a problem for many of the electronic devices that used batteries.

A related reason for abandonment is the stigma associated with using a piece of equipment that identifies users as ill, sick or weak. Many people prefer devices that look like they belong in mainstream society and don't "stick out" as being disability related. People have mentioned they do not want a wheelchair or scooter that looks institutional.

“I have a talking thermometer and I haven't been able to get a battery for it. I don't drive and I don't know where to take it to get the battery changed in it. I can't even get it apart.”

Other AT service providers did not consider evolving and changing AT needs for this population. The rate of disabilities increases with age and “disability takes a much heavier toll on the very old” (Health, health care, and disability

[AOA], 2002). Thus, it follows that AT needs can often change with age. Unfortunately, this was not always considered when older adults were receiving their AT equipment. As these changes occurred, new problems emerged and old equipment was not always useful.

“That’s one of the things that I think is true of a lot of people as they age is they may not need the same AT devices continually but for problems that creep up temporarily and sometimes that’s a real problem...”

Strategies for Improvement

In general, consumers are interested in seeing AT being sold at reasonable costs. For the majority of consumers, when funding processes are lengthy or when potential funders refuse to pay, consumers must do without. If assistive technology were more affordable, not only would more people be able to afford it, but funding streams might also be easier to deal with. Social programs that provide AT could potentially be able to afford more equipment and thus help more consumers if the costs were to go down.

Consumers would also like to see a society better educated about disability-related issues. Professionals and the public need to be trained in disability awareness to help change some of the negative attitudes consumers are facing.

“‘These people are crazy.’ That’s one of the things [the doctors] said; that psychiatric patients like to be in and out of the hospital.”

“Well I was covered under an HMO plan and they also felt that nobody had ever died from hearing loss, and they wanted me to just sit back and accept that I was getting old...”

*“Yeah, I have had them tell me to get a job too, and I’m like, **Hello! How am I supposed to see what I am doing?**”*

People need to be better educated about disabilities to increase the levels of acceptance, knowledge and awareness. As professionals become better educated about their consumers and patients, they will become better qualified to provide services to the disability community. For example, if building professionals were trained to include features such as railings, curves

for walls and modified hinges, older adults and people with disabilities would be better able to navigate buildings. As employers become better educated, they can learn how to hire and work with people with disabilities.

Participants would also like to receive training for their devices. Most consumers agree that if AT is purchased, training should come with it. Unfortunately, that is not always the way the process proceeds, and many consumers are left with equipment they cannot fully utilize.

“If tutors are needed to help you learn how to use your AT, that is a service that should be available...now you have paid all this money for a computer that you don’t want anyone to touch because you’re afraid something is going to get messed up.”

When rural participants were asked what immediate changes they would make if given the power, some consumers expressed a desire for more income. With increased incomes, consumers could potentially engage in activities currently restricted to them. For example, a few consumers reported interests in going to school, but were unable to because they could not afford the transportation costs to attend. Increased incomes could make options like these more viable.

Conclusion

While some barriers are particular to certain populations, overall it is clear the majority of issues related to disability and assistive technology use are the same. One of the biggest barriers mentioned by CR4AT focus group participants included the knowledge and the attitudinal barrier, especially from professionals and employers. This involves a major meso level change. Many of the barriers mentioned in the previous section could be addressed if there were a higher level of public awareness concerning disabilities in general and each individual population. Better attitudes could be the good faith start to making sincere change in the way people are treated by funders and social programs.

People in all of these populations were able to enjoy the benefits of the assistive technology they currently used. If the numerous barriers they have shared could be systematically addressed, changes at both the micro and macro levels could occur. Better policies could be put into the place that could address the slow acquisition processes and maybe reduce the inflated cost of

equipment. More consumers would be able to share the numerous benefits shared by these focus group participants and perhaps then there could be a compilation of AT and disability success stories instead of a list of barriers.

It unfortunately appears that some/many people with disabilities in rural California are not connected to their communities. Multiple barriers exist that have created this disconnect. The biggest of these is public attitude. Public awareness of disability was something many participants desired. In many cases, this could be the first step to addressing many of the other barriers. When people become more aware, they can see how the lack of adequate and accessible transportation impedes work, health and life. When the community does not actively pursue an agenda that includes their residents with disabilities, exclusion persists.

AT on the Job

The Difference Technology Makes

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

“The talking and Braille computers really contribute to my being able to do a job because I can store information, organize information and retrieve and research information from the ‘Net’ by using talking and Braille computers. I also give presentations by using the Braille computer to read my Braille notes. By using those types of AT, I am able to manage information to successfully do a job.”

Background

In the last few decades, technology has transformed virtually every aspect of our society. Particularly in the areas of communications, transportation and healthcare, technological advances have had a monumental effect on how we all live in today’s world. These changes occurred at both the macro and micro levels, with infrastructures connecting distant computers and individuals learning new skills.

The effect of the advances in technologies on people with disabilities is exponential in both positive and negative directions. With the right technology lives are dramatically improved but without access to technology lives can be significantly worsened. On a daily basis we witness new ways in which technological advances enable people with disabilities to more fully participate in all aspects of work and daily living by performing tasks previously considered beyond their capabilities. These advances in the lives of people with disabilities don’t simply impact the individual’s capabilities; they also reorder social perceptions of persons with disabilities. In addition to helping to create a new social view of persons with disabilities as capable and contributing members of society, these technological advances have also contributed to a positive change in the way in which individuals with disabilities view themselves, and indeed the entire disability community’s cultural identity.

The Community Research for Assistive Technology (CR4AT) researchers had previously identified several major gaps related to the employment of persons

with disabilities. These include:

- A lack of awareness of the benefits of employment for individuals with disabilities.
- A lack of universally designed technology that creates lower-cost devices to assist in employment settings for those on limited incomes.
- Policies that govern access to AT for the workers who are disabled lack comprehensiveness, are not sufficiently consumer-oriented and require better coordination to create an accessible system of procurement.

Specific questions CR4AT raised about employment included:

- What are the barriers to employment that AT can remove?
- Does AT improve employment outcomes?
- Who pays for AT?
- How can AT assist those who work at home?

Answers in response to these questions ranged from simple to extremely complex. Our focus groups confirmed what we already knew: AT does improve employment outcomes for persons with disabilities. AT provides functional value, enhances productivity and increases physical and mental health. We also found there are many barriers to using AT in employment for persons with disabilities. Education of employers, co-workers, and the general public is needed to demystify disability and the use of assistive technology. Societal level changes and structural changes need to succeed if individual level changes have a chance to succeed. In addition, funding sources for AT need to be streamlined and a standardized system should be adopted within funding agencies to aid those acquiring AT. Another major finding was the fact that AT does not need to be deemed “special,” but rather, if more products and devices were universally designed for a broader range of abilities, then the AT system would be vastly improved. The market for “special” technology is tiny in terms of comparison but the market for universally designed equipment or systems is enormous.

When asked what types of AT are used for employment, the majority of the respondents revealed that a variety of devices are used. Adapted computer hardware and software, such as roller ball mice, flat screen monitors, large monitors, screen reader programs such as JAWS, and other adaptations were noted. Ergonomic office furniture, such as adjustable desks and keyboard trays, was common. Mobility aids such as wheelchairs, canes, or crutches

were used by a variety of participants to enable them to be mobile both on and off the jobsite. Devices for the hearing impaired, such as amplified telephones, were frequent. Conventional technology like personal digital assistants (PDAs), cellular phones and tape recorders also enabled those with disabilities to perform their job functions effectively. One respondent noted:

“I use my computer with different types of programs and I use a mouse—it is a little bit bigger than your average mouse. I have a reacher so that I can pick things up and grab things off of the floor if I need to or whatever I need to get to work.”

People used power wheelchairs to go to work or other necessary places in the community, and a lift-equipped vehicle was essential for people using power chairs. Hands-free phones and other communication devices allowed consumers to work and communicate at the same time. An individual might use multiple AT devices for support, assistance, and enhancement of job performance.

AT in Employment: The Importance of the Ecological Model

At the individual or personal level, focus group results found that employment provided meaning and a sense of self-esteem to many respondents. Improved physical health, enhanced mental health and an increase in independent living skills and abilities were also identified as direct results of a person with a disability being employed with proper AT to aid them in performing their jobs. This contributed to individual income and access to benefits for a number of people with disabilities. Functional ability and AT were closely related in terms of being able to do daily activities at work without assistance from others. This led to individuals feeling more independent and more capable of participating in the workforce, despite the beliefs of many that, “disability is synonymous with needing help and social support, reinforcing associations between disability and conditions of helplessness, incompetence, and the perpetual receipt of various forms of assistance” (Orange, 1997).

People’s health was positively influenced by the use of technology in the workplace and through the provision of alternative work options by employers. For example, for employees who fatigue easily, employers provided additional breaks and other non-AT related accommodations. Job related tasks were made more comfortable and easier to accomplish by the use of AT, which in turn provided an increase in productivity in the workplace for both the

employee and employer. When AT and reasonable accommodations are provided, tasks are completed on time and people with disabilities do not have to exert as much energy with the use of AT to complete the task than without the AT, which leads to improved health.

In addition to physical health, mental health was also improved by the use of AT in the workplace. A healthy sense of self-esteem and an ability to consistently strive for better opportunities and increased independent living outcomes is gained from actively engaging in sustainable employment through the use of AT. There is a sense of inclusion in society through employment that breaks down the marginalization of persons with disabilities in the workforce, and society as a whole. Self-determination is a major goal for people with disabilities and AT contributes to more options and a wider range of choice. With employment, a person with a disability is able to contribute to determining his or her own destiny and is able to live a better and fuller life than the alternative—getting by on limited funds from government or private social programs.

According to one focus group participant:

“Well, I have a job I work for the county and I have been there for over two years and the way I see it right now is that I know I can do better than that but it takes time to build up your skills and to get the job you really want to get but to do that I have to build up my reading, writing and math and this is helping me to move to the next step ahead. I never thought that I would get this far in life; I have a lot more hope.”

Appropriate assistive technology can increase self-efficacy and give people a belief in a better future.

While AT has a major impact at the individual level by enhancing job performance and mental and physical health, the use of AT to access one’s community and place of employment influences how a person with a disability accesses and interacts with their environment. On the service level, there is a call to examine the disabling environment rather than examining personal limitations (medical model) or functional limitations (economic model; Orange, 1997). By creating accessible environments, people with disabilities can better become gainfully employed. Participants revealed the need for specific AT in

employment settings. For many, the needed accommodations included universally designed changes to their office spaces, such as windows for natural lighting, relocation of cubicles, and creating a more centralized source for common resources used by everyone in the office.

One focus group participant said:

“If I had ample money, if money weren’t an issue, I would find a location closer to public transit, I would centralize the supplies, and have all ergonomically designed equipment and furniture for everyone. I would try to address the needs of every employee, including those who aren’t the normal AT user.”

At the service level there is also a need for employment counseling and services delivered effectively to disabled consumers. AT services need to be accessible and supportive for people seeking employment. Community agencies, including Independent Living Centers are part of the system level that needs to change to ensure AT is made available when needed. Employment is a vital component of every adult’s life. For many with disabilities, seeking employment is too often experienced as yet another adversary encountered on the road to independent living. By looking outside the person’s disability, and focusing more on altering the environment to accommodate one’s needs, employment for persons with disabilities is not only possible, but it increases inclusion of the disability community into society.

On a societal level, systemic issues surrounding disability were uncovered. The use of universally designed products and services was recounted several times. Universal design is defined by the Center for Universal Design at North Carolina State University as “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,” (CFILC, 2001). 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, (CFILC, 2001). “Another example is the use of volume amplification on telephones. This was originally designed for individuals who are hard of hearing, but it has proven to be very helpful to everyone using telephones in noisy environments such as an airport” (Alliance for Technology Access, 1999).

One respondent relayed her or his experience with universally designed products that enhanced job performance and improved the participant's customer service skills on the job:

“Of course things like the phone help me, hands free phones are just a blessing to me; and the other thing, we have devices and things around the store that I use—the little shopping baskets, if I’m assisting a customer for things they actually give me things to put in the basket to carry for them.”

As more universal design principles, parameters and products are incorporated into legislation, the need for major redesign and architectural accommodations in the workplace will decrease, allowing more persons with disabilities to access and obtain employment opportunities. At the macro levels there are also issues of design, policy and attitude. There must be a political will to implement programs that support people's employment through technology. Attitudes toward both AT and people with disabilities need to change to ensure that AT will support the employment goals for people with disabilities. Employers' attitudes need to change in terms of being willing to hire disabled candidates and provide them with necessary equipment. Policy changes at the federal and state level are also essential to standardize the availability of AT.

How Do People Obtain AT?

We asked AT users how they obtained and paid for their equipment, how expensive it was, and what, if any, problems they encountered in securing funding. We found that devices were funded through a variety of sources. Some people paid for the devices themselves or were helped by their employers or the California Department of Rehabilitation, while others relied on their health insurance provider to buy the AT needed in the home, which also aided at work.

Some of the focus group participants acquired their AT through self-advocacy. They knew what types of devices worked for them, and were able to define their needs. They conducted research with the help of the Internet and co-workers in order to locate the appropriate devices to aid them in their employment and education.

“I went to the wheelchair evaluator's and I pretty much knew what style I wanted and what I wanted on it. The equipment that I use at

work was recommended to me by a coworker who helped me research equipment and pick things out.”

Participants reported that they paid for much of the AT they used both at home and on the job themselves. Common or mainstream items such as computers, cell phones, and PDAs were the most commonly identified of these kinds of items. Prices ranged from under \$50 up to \$1,600 for the devices they purchased out of pocket.

A small percentage of the participants had AT devices funded through their employers. One hundred percent of these respondents had a positive experience with the employer paying for devices. Employers were found to be quite willing to purchase the devices people would need on the job. Some had exceptional experiences where the AT was bought for the employee before the employee even started work.

“Now the job that I have now, they got the assistive listening device before I even started the job, I just mentioned it and gave them a flyer on it and they went ahead and got it before I even got the job.”

Health Maintenance Organizations (HMOs), Medi-Cal and other insurance agencies had purchased equipment that consumers used in getting to work, being mobile on the jobsite, and for activities of daily living. The most commonly used devices were wheelchairs and other mobility devices. Much of the equipment that a person needs is not only work related, but also used in the activities of daily living. Expensive mobility aids, like wheelchairs were most commonly funded under the term Durable Medical Equipment (DME) from a large healthcare insurance plan, such as an HMO, Preferred Provider Organization (PPO), Medicare or Medi-Cal, although these items sometimes have strict restrictions on use. Often the HMO insurance expects a co-pay so individuals need to contribute out of pocket.

DME is defined as “medical equipment that is ordered by a doctor for use in the home. These items must be reusable, such as walkers, wheelchairs, or hospital beds” (Medicare, 2003). For example, an item like a wheelchair must be for use only in the home to be funded through Medi-Cal. Say for example, someone has limited mobility and needs a scooter to get from his or her house to the bus to work. Often, health insurance will not cover the needed AT. However, if the scooter can be used in the home, then these agencies usually can cover it. Nevertheless, it must explicitly state in the request that the item is

only for use in the home. Much to the chagrin of many people with disabilities, the needed devices that are covered under these healthcare plans often take months to years to receive. This wait further impacts one's ability to join the workforce with the AT necessary to conduct the activities of the job in an efficient and productive manner.

"The amount of my AT computer and mouse was I think \$1400 in that area and as far as the process, it was like a three to four week process relatively easy to my employer, so that was the good part, but when dealing with other AT, it's rough, especially with Medi-Cal."

The California Department of Rehabilitation (DOR) was not commonly mentioned as a funding source for AT in employment. However, for those who did receive funding for AT through DOR, there were mixed experiences of both positive and negative. Some people easily received the services and devices they needed from DOR.

"I went to Department of Rehabilitation and they sent me to an access center to be evaluated and that is how I got my note taker and I also got a computer and now they are setting things up so that I can go to a computer class now that I have my own computer because I am about to start a new job."

For others, obtaining AT through the DOR was a difficult process. Due to the length of time it takes to receive AT for services, DOR was not a successful funding source for many participants in the focus groups. Often this was seen with larger, costlier items such as wheelchairs and modified vehicles.

"There was a lot of time involved in the van and the power chair. When dealing with the HMOs or DOR, my [modified] van was a two-year process. I had to go through a lot of stuff to get to that point. When you have [to get] all of your equipment and safety features, those things tie you up for days and weeks it seems like. But I didn't have any hassles when it came to the employer paying for the [other] equipment."

Funding AT is quite complicated and often involves great time delays. Participants had varied experiences getting their equipment funded. For some, it was a relatively quick process from getting the referral to receiving the

device. Commonly, however, acquiring AT is a long and arduous process that can last months or even years. Many reasons given for not being able to get devices funded is the lack of funding sources, ineffective services from the funding sources, and the amount of time one has to invest in the process. It can be concluded that the smaller, less expensive items needed as accommodations do not seem to be a problem for persons with disabilities. It is the larger, more expensive AT devices that prove difficult to obtain through the various funding agencies, such as DOR or Medi-Cal. For more information regarding the many issues associated with funding, see the chapter titled, "Funding & AT." This section only examined funding issues for AT used for employment.

How Does AT Successfully Impact Employment?

We were happy to learn that many individuals' lives have been enriched by having access to AT. Focus group participants were asked how equipment helped them access employment, including self-employment, and the difference that having AT has made in their work lives.

Due to having AT available to them, several individuals reported that they could become employed or become more employable than they had been without AT. Several respondents mentioned that the use of AT allowed them to get to their worksite by using adapted private transportation or by using accessible public transportation. AT was reported to enhance effective communications on the job and computer-aided technology helped many individuals in performing their job functions at the level that was expected.

"Without the technology, I don't think I would be employed today. It has allowed me to perform the essential functions of my job and keeps me informed on the AT that is out there. Before I worked here, I did not know the Quadjoy³ mouse existed and it has allowed me to again become a full-time employee."

For many participants in the focus groups, the functional value of using AT was closely related to productivity on the job. Persons are able to work longer at certain tasks with adapted equipment than they would without it. AT helps

³ A 3-inch joystick with sip-and-puff "A-B" buttons that a person with limited mobility can use to operate a computer. For more information, see the Quadjoy Web site (<http://quadjoy.com/>).

decrease pain and fatigue. Communications aided by AT also had an important functional value on the job. For those who are hearing impaired and wear hearing aids or need amplified telephones, they were able to receive those devices and work more efficiently, and in some cases advance into upper management positions.

Mainstream devices such as cellular phones, personal digital assistants, and laptop computers are everyday devices that enable persons with disabilities to function and perform well in their current employment as well as obtain employment. These devices become vitally important and necessary for persons with disabilities. Because they are not considered “special equipment” many persons with disabilities have incorporated the use of these devices into their daily routines at minimal cost.

“It has allowed me to do everything I need to do as far as what’s in my job description, having six counties to travel; if I didn’t have my accessible vehicle I wouldn’t be able to get to all of those locations, doing state wide and national activities; again, the vehicle is tremendously important.”

This consumer also used a PDA, cell phone, and computer to keep organized, communicate, and enhance productivity at work. AT for employment need not always be “specialized” equipment; many popular devices that are available to and used by people without disabilities are especially important tools for independence for persons with disabilities.

“By going from the pushchair to a power chair I am exerting less energy. The power chair allows me to be more productive. I experience less fatigue.”

The Internet and e-mail have created an equitable playing field for both those with and without disabilities. The introduction of the Internet has allowed people with disabilities to disclose their disability only when it becomes necessary. This in turn has created a major change in the way others view persons with disabilities, and how people with disabilities view themselves.

As one key informant stated,

“You add the introduction of the Internet and suddenly I am on equal ground with everyone else. It’s interesting because another

part of what I do is have to answer questions and talk to people by e-mail, and input forms; what is interesting is I can actually introduce my disability when it's relevant. But until I introduce it, I'm not seen as a disabled person. It's been interesting to watch the kind of effect because all my life I am used to people reacting to my disability first, and then me. Whereas, on the Internet, it's turned around and they get to know me first and when it's relevant, I get to introduce my disability" (P. Hoye, personal communication, July 8, 2003).

Still Striving for Success

Participants were also asked about the barriers they faced in employment using AT. An employer's perception of disability, the perception about the cost of reasonable accommodations, the lack of training on AT devices for the user, and problems with repairs and fitting were all problematic areas.

Negative employer perceptions of disabilities impact employability for people with disabilities. Discrimination by employers against persons with disabilities seemed to be a common occurrence in the job hiring process. Employers were not able to determine disability by looking at a resume. However, when the person with a disability was called in for an interview, the common experience with many respondents was that the employer was taken aback and unprepared or unwilling to hire a person with a disability. Consumers felt that the employer's negative perception of disability should be tackled through additional education and training for employers rather than just a review of the laws surrounding employment for persons with disabilities, such as the ADA. But rather, a better approach needs to be made at showing that disability is not something to be feared. Moreover, persons with disabilities felt that not only do employers need to be educated regarding disability awareness and sensitivity, but coworkers as well.

"Sometimes we need to educate a company's fellow workers and not just the employers. Someone may need an extra break as an accommodation—people shouldn't tattle on someone who needs an extra break. There may be good reasons."

In addition to getting past the interview, persons with disabilities relayed that they experienced a reluctance on the part of employers to provide accommodations, often because employers were misinformed about costs and

did not understand that accommodations or alternatives could be made in a cost-effective manner for the company.

Professional training on their AT devices was a requirement expressed by many focus group participants. However, training proved problematic. The time investment to train on AT devices for employment was often seen as lengthy for both employees with disabilities and employers. In some instances, employees were provided with the equipment; but it was never properly calibrated to work with other devices. When no training is provided on the proper usage of AT devices, it negates the entire purpose of having AT to aid in performing functions on the job.

“Yeah, I can type in messages and everything on it, I know how to use the Braille note, but we have never taken it to the printer and I don’t know how to hook it to a printer.”

“The roller ball (mouse) helps eliminate stress on elbow; voice-activated software is goal for self, but is time-consuming to train system and to learn.”

Moreover, many persons go without the needed AT in employment because they are afraid to ask their supervisors for accommodations. In several focus groups concerning employment, it was revealed that many people just simply did not ask for the devices they needed, and many lost their jobs because of it. Others asked for the accommodations, and were accused of complaining and asking for too much.

“But it’s like you’re afraid to complain and when I did my boss threw my paperwork at me. I asked to be transferred out of the unit. And then I ended up with a very nice boss. When you get discriminated against when something bad happens, it’s hard to ask.”

Instances of sexual and racial harassment are prominent and well-publicized examples of the difficulties an employee with less power can encounter when trying to contend with a senior person with more power. Disability discrimination is another form of employment harassment. No one should have to be uncomfortable requesting equipment that one needs to do one’s job.

Transportation proved to be another problematic area for many when it came to employment. As was repeatedly stated, “one cannot be employable without

the ability to get into work.” Unfortunately public transportation is unreliable in many areas, and being late or not showing up to work is not an option for many people and causes adverse effects on their employment status. It would make sense if people without adequate transportation could work from home or telecommute, but this does not seem to be common among the people we interviewed. According to one of our key informant interviews, “California is the culture of the automobile.” Public transportation is limited at best in a city and nonexistent once you get outside of the greater city limits. While busses and other public transportation have made many strides in making their system accessible, service is still limited in suburban areas and almost nonexistent in rural areas. Dr. M. Clark commented (personal communication, July 11, 2003):

“They understood the first time I was late, but if you do it too many times, you are screwed and they are going to try and work something out where I don’t lose a point. I’m at their [transportation service] mercy waiting to get picked up.”

What Happens When AT Is Not Available?

We wanted to learn more about what happens when equipment is taken away or not available for use, either because it is broken, needs repair or is in the process of being replaced. By not having the proper equipment, not only is work productivity negatively influenced in employment, but also health and function are adversely affected. This issue arose most when consumers’ AT had broken down and needed repair or replacement. Broken equipment or equipment sent out for repair or replacement can place an undue burden on the person with a disability who relies on that equipment to perform well in their jobs every day. Outcomes include the inability to work at all while the equipment is unavailable, not being able to produce the quality of work that is set for an employee, and a decrease in functioning or an increase in pain. As one participant confided:

“I had trouble with a computer once on a job and I was off for three days.”

When asked what would happen if the AT a person needed was out of order and unavailable for use, participants revealed a myriad of responses. All responses detailed that the person could “get by” without the AT if they “had to,” however, respondents stated that daily functions would be more time

consuming and difficult, and their employment options limited.

“I would survive—I am always a survivor— but I would have to go back to the cave men days of doing things. Back to manual wheelchairs, back to a vehicle that I will have to transfer myself from the vehicle, I would have to fold the chair up and put it into the vehicle. I think I would be able to find a job, but I am sure I would be under-employed in that situation so it wouldn’t be a job to where I can make enough to support my family and myself.”

For those participants who previously had equipment break down and it was not available for use at work, they felt a profound sense of loss and realized the extent to which they rely on their AT to perform well in employment.

“For me, I use PowerPoint to teach, and I found out just how much I needed it when the power point [projector] bulb went out. So it showed me how hard it was.”

“I have been stuck at work all day with no batteries for my hearing aid and I can’t function; when the battery goes, you’re gone, you’re done.”

Respondents felt that employers recognize the financial benefit of having employees with proper AT accommodations. In employment, when a device breaks down, it not only affects the functional aspects of the job performance, it also impacts the productivity of the employee who uses the device. When work does not get completed on time or in a consistent manner, not only are there problems for the employee, but also the employer. Suffice it to say, situations like this can cause a performance issue for the employee and ultimately the loss of a job. One participant, while interning, was prevented from completing projects on time due to equipment problems and computer malfunction. The participant was not able to function independently without reliable equipment and would rely upon last-minute assistance from managing personnel. The respondent stated that employers were “not impressed” with this situation, and did not choose to hire the participant permanently after completing the internship. A failure in AT that a consumer relies upon can be detrimental to a person’s employability. Individuals will not be hired if they cannot compete, and often the key to performing well in the workplace is finding the right AT.

Strategies for an Effective AT System

We also asked people what they wanted to change. It was everything from individual skills to systems and services to policy change. Consumer education, employer education, and professional training were mentioned numerous times. In addition, participants in the focus groups wanted to see policy changes enacted that would create standard eligibility criteria from the funding sources, universally designed devices from manufacturers, and a large-scale, public education campaign about disability issues.

While AT has enabled many persons with disabilities to gain employment, there are still some areas for improvement when it comes to “matching” equipment appropriately. Some, but not many, also felt that aesthetics were important and that equipment should look less medical if possible. For some, it’s about the ease of using the equipment, or having the equipment compatible with standard office equipment, such as a computer or telephone. Others would like to see AT that is more portable. Almost all of the participants would like to see an improvement in the services they receive for repairs and maintenance of the equipment as well as equipment that is functioning in a consistent manner.

“If I have a product that can increase my independence with the greatest ease while in use, being easy to plug in or unplug, also portability, anything efficient and un-facilitated will make me happy, just ‘plug and play’.”

Educating employers about both disability issues and AT was a frequent theme. The most common and relevant concerns included:

- Exposing the real and perceived costs associated with accommodating an employee with a disability
- The employers’ responsibilities to provide information alternatives
- Combating discrimination against people with disabilities by educating the general public on disability issues via public announcements, and more exposure to the disability community

We received a cross-section of responses in regards to education on employment accommodations and employing persons with disabilities. In terms of public education, the respondents believed that disability needed to be demystified for the general public: non-disabled persons and employers.

“If I had a magic wand I would change society’s attitude about hiring people with disabilities.”

“I think education, period, just would enlighten us on things. I would like to take them and put them in a [wheel] chair for half a day and tell them to deal.”

Participants also felt that more assistance could be provided from agencies that promote employment for persons with disabilities, such as the California Department of Rehabilitation. We received responses relaying that consumers felt the Department of Rehabilitation could be conducting more education and outreach with local employers, letting them know and understand the benefits of hiring persons with disabilities and easing their fears or concerns about the cost of accommodations. Consumers also wanted to see the Department of Rehabilitation encourage employers to use the department’s resources for hiring, a practice consumers thought wasn’t occurring regularly.

“I think that this information should be available to the everyday employer; they need to be educated to hire people like us. I don’t have a lot of experience and I don’t feel like DOR is trying to help me get any.”

“AT really isn’t as expensive as most employers think it is and even the simplest items can be considered AT that will enable someone to perform their job like it should be performed; it’s just an attitude change that we need.”

CFILC was not mandated to focus on education in this project but it has direct relation to employment for people with disabilities. Moreover, once disability is demystified, education on AT is also needed, from the concept of expensive and high-end, to something defined as useful for all, not only those with disabilities. In addition, AT needs to be looked upon as just another tool in the step to employment instead of “something special.” Dr. M. Clark suggests (personal communication, July 11, 2003):

“A two-prong attack: tax incentives for employers and offer workshops in the industry and in the community to educate everyone. AT is not a scary thing. People don’t understand what AT is. They think it’s the high-end, super-duper computers, but more

often than not, it's just down and dirty ... figuring out what is the cheapest way to achieve the task."

"I would probably look at universal design to try and educate employers so that they understand more and are able to access more as far as being able to see that type of productivity. It is important to me that they see that."

A common suggestion that prevailed not only in employment issues, but through all focus group topics was the need for a national system or standard related to AT. The need for funding agencies and others to standardize the definition of AT exists. This definition needs to look at the practical uses of AT in a more broad fashion so that AT usage encompasses more than the medical model. Respondents felt that if change were to truly occur that it would need to begin at the higher levels of leadership, who then could set and implement policy.

"Change has to happen at the leadership level for it to trickle down, so I would look at the states, countries and counties to change their attitudes on hiring people with disabilities. When they change, the attitude will trickle down and change people's opinions on people with disabilities."

Because the funding agencies follow the ingrained philosophy of the medical model, the time it takes to get devices funded can be incredibly long and grueling. The suggestion was made consistently to streamline the funding process by making the forms available in various agencies and online, as well as cutting down the time it takes to receive an answer regarding the funding of devices.

"I would like to see when you apply for devices to have a shorter turn around time, instead of waiting 60 days for them to tell you that they don't know if you can get the device or not, then you have to wait another 30 days to find out what they decide to do, then it takes another 30 days for the process to go through. It is such a long process and they keep saying, 'We have so many of you.' I know a lot of people who have gone through that [wait]."

As much of the technology that was originally intended as AT is becoming more and more mainstreamed for non-disabled users, there is a wider

acceptance of these devices. However, devices intended solely for those with disabilities still carry a stigma that non-disabled persons have a hard time accepting and using.

“The technology that was most beneficial was what the hearing people were willing to accept. They gave me a TTY when I’d been there for 9 years. Nine years later two people in the school district had called me on the phone in all that time, because they refused to use the Relay. E-mail came in at the same time and ALL of my communication became e-mail, and that saved my job. Because the TTY was a deaf device and e-mail was not.”

Cultural Access

AT Among Ethnic Minorities

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

Introduction

When examining the lives of people with disabilities, ethnicity can play an important role. Previous research has shown that members of ethnic minority groups have higher rates of disability than their Caucasian counterparts (Fujiura, Yamaki & Czechowicz, 1998). Factors such as language differences, education and literacy levels affect the types of jobs people can attain. In these communities, these barriers may limit people to low-wage jobs and dangerous labor, increasing the risk of disability and injury (Smart & Smart, 1997; Miller, 2002; Santana, 2001). It is due to these factors that national disability rates for ethnic minorities are much higher than for Whites (Bradsher, 1996).

The State of California is one of the most diverse states within the United States of America. The U.S. Census Bureau (2000) reports the following data from the 2000 Census reflecting the demographic makeup of California⁴:

- 59.5% White
- 32.4% Hispanic or Latino
- 10.9% Asian American
- 6.7% Black or African American
- 1.0% American Indian and Alaska Native and
- 0.3% Native Hawaiian and Pacific Islander.

Nationally, the percentage of people with disabilities according to ethnicity is as follows:

- 18.3% White

⁴ For the purpose of this paper, the following ethnic groups will be discussed: American Indians, Blacks or African Americans, Latinos or Hispanic Americans, and Asian American and Pacific Islanders. While the author recognizes these ethnic groups include many diverse sub-populations, this discussion will refer to these terms because they correspond to the United States Census data and much of the current literature within the realm of the social sciences.

- 20.9% Hispanic or Latino
- 16.6% Asian American
- 24.3% Black or African American
- 24.3% American Indian and Alaska Native and
- 19% Native Hawaiian and Pacific Islander (U.S. Census Bureau, Disability Status).

Unfortunately, the use of assistive technology (AT) by members of ethnic minority groups has not been fully researched. For this reason, the Community Research for Assistive Technology (CR4AT) project decided to examine the use of and barriers to AT by members of these populations.

While performing preliminary research, the California Foundation for Independent Living Centers (CFILC) identified the crosscutting issues of problems affecting ethnic minorities and the complications of funding. These two areas were added to the research agenda very early in the research process. Goals in working with consumers from these populations included the following:

- Making this research inclusive and sensitive to the needs of ethnic minorities
- Representing the population in California to the best of our ability, through ongoing outreach and efforts to over-sample
- Understanding how AT is or is not effective for ethnic minorities

CR4AT organized the sessions by a variety of population types, including African American, Asian American/Pacific Islander, Latinos, and American Indians. Focus group questions for the above populations included:

- Why are some types of AT accepted and others rejected?
- How could equipment better suit you?
- Who pays for AT?
- Why might people prefer to go without AT?

The research design used allows members of the disability community to guide the focus of the research process. All research participants are made aware of the research and actively contribute to its direction and outcomes. This design strongly contrasts with the “conventional model of pure research” where participants are treated as passive subjects and information is simply taken from them (Whyte, 1991). Community researchers facilitated and took notes

during focus group meetings and also coded the qualitative results using a method they learned through training with CFILC. CFILC staff and CSUN university researchers also did coding, and a high degree of inter-rater reliability was assessed. Members of the research team included individuals who spoke English, Spanish and other languages, as well as people from different racial or ethnic backgrounds.

Use of AT by Ethnic Minorities

Different technologies were mentioned within each population. In the American Indian focus group, six devices were mentioned: an ergonomic chair, a computer tray, an ACE wrap, crutches, an ankle lock, and lab shoes. For African American consumers, the most popular items were canes, wheelchairs, scooters and walkers. Within the Latino population a multitude of AT was mentioned. The most popular items included canes and computers (including adaptive software), but a wheelchair, stress balls, and talking devices such as clocks and microwaves were also mentioned.

Using AT, consumers were able to interact with their communities by venturing out of the house and building social relationships with others. Many people would be homebound or restricted to their beds without their devices. Before receiving his AT, an Asian American consumer spent his days watching television. Upon receiving a computer art program, the consumer began to make cards, banners and other creations for others.

Participants were also able to enhance their employment with assistive technology. In the American Indian focus group, one person received an ergonomic chair and a computer tray to make her workstation “ergonomically correct.” Prior to receiving this equipment, this participant wrote everything out by hand because using the computer was not comfortable.

“I was doing nothing but hand-writing for a long time until I had a computer tray put in and the ergonomic chair.”

With this equipment, the consumer was able to increase their work hours from 20 to 30 hours a week and increase her level of work productivity.

Assistive technology also promoted better health outcomes for focus group participants. People reported less pain when their AT devices were available to them. One American Indian consumer spent portions of her workday lying on

the floor in pain before he or she received his or her AT devices.

“I would end up lying on the mats in the middle of the days. When I was full time I used up all of my sick leave and vacation and I was back and forth between half and full time trying to keep working and not knowing which way to go. So I also used the mat to lay on. Using the computer and lifting was causing me a lot of pain.”

Using the appropriate AT could reduce the amount of pain consumers experienced in their daily lives. People also used AT devices to improve their health. One Latina consumer used a number of devices, to strengthen her muscles.

“I have hand motor loss resulting from an accident that causes my hands to go numb. I use stress balls for squeezing exercises, I type on the computer for exercise, and grip and release things to make my hands stronger.”

Assistive technology not only affects pain and physical health, but mental health as well. For these focus group participants, using AT meant increased access to employment, the community, and much more. Conversely, when asked how life would be without their devices, many responded, “depressing.”

“I don’t think I would be able to survive [without my stress balls]; my hands would probably be numb. I’m sure my stamina would be affected, and I know that I [would] get depressed.”

Without AT, many activities became less feasible. Not only would functionality be decreased, but so would work and play. For many participants, their current quality of life was due at least in part to AT. Appropriate AT also impacts the success of people in education, employment, and independent living. Without AT, consumers’ quality of life decreased and they became less active, less healthy, and less productive. Subsequently, self-esteem levels dropped and people can become depressed.

How Do People Get AT?

Overall people with disabilities from African American, Asian American, Latino, and American Indian backgrounds reported using similar funding streams to those used by the general disability population. Combined, the four ethnic

populations used a variety of channels.

Many participants reported using health insurance and medical benefits to purchase their devices. This funding stream appeared to be especially popular among African American and Latino consumers. Most of the African American participants used Medi-Cal as a source of paying for their AT. Sometimes this funding stream was used in combination with others, such as with Medicare or another form of health insurance. The medical routes of Medi-Cal, Medicare and doctor referrals were also popular among the Latino populations. In addition to these health avenues, African Americans also benefited from Veterans Administration (VA) benefits and HMO coverage. We did not have adequate information on Asian Americans to report their use of funding.

The California Department of Rehabilitation (DOR) was an often-mentioned funding stream among the Latino population. People obtained a variety of devices using this method, including: a laptop, talking scales, white canes, and a Braille labeler. While the speed of the process varied from a few weeks to a number of months, consumers appeared to be happy with their experiences overall. This is particularly interesting, since other groups of participants had less positive things to say.

Members of the four ethnic groups also used other methods of funding. A few consumers were able to obtain devices through other agencies. One African American consumer was able to get a free adaptive telephone through a local Independent Living Center (ILC) referral. A few Latino participants received devices from other agencies, such as the Braille Institute. Not many participants in this group discussed using their AT for employment activities. Subsequently, employer funding of assistive technology was rarely mentioned. This is also important since employer-funded accommodations are extremely important to ensure access to jobs.

In other cases, the consumer or a family member purchased the AT. Although not a frequent funding source, it was mentioned in the African American, Asian American and Latino focus groups. The reasons for paying out-of-pocket varied. Sometimes consumers bought devices after being refused by another funding source. Another Latino consumer purchased “smaller-end items” using personal funds and used DOR and other agencies for the more expensive items.

Some participants sought alternative funding for their devices. A few people

were able to borrow AT. One Latino consumer was able to borrow a cane from his landlord. Another participant received scholarship money to pay for AT.

Success Stories

Many of the lives of consumers in these focus groups have been enriched by the use of and access to AT. In CR4AT focus groups, participants were asked to share how assistive technology has affected their lives. People reported success in all areas of life, including employment, function and especially independent living. One Latino consumer with a spinal injury told a detailed story of how he or she got off of the floor. After multiple miscommunications between the participant's physician and physical therapist, he or she was finally able to obtain the needed AT, a wheelchair.

“After I went through all of that, I got this anger to fight, to get ahead in life and I did everything possible to succeed. I’m an activist in the community, president of the PTA, and very active in the community. When [the specialist at the ILC] calls me and says a chair has been donated, I pick them up and give them to someone else. The inspiration in my life is what I do for the community, especially for people in this area.”

When people within a close community have a very positive experience, they are very likely to share this with others. With the proper equipment, this consumer was able to not only become active in the community, but to help members of the community as well. People from ethnic minority communities may be more receptive to information from fellow community members; therefore word-of-mouth may be a very valuable communication tool. Building a trusting relationship is essential for working in communities that have been marginalized or traditionally underserved.

Why Do People Stop Using AT?

People may stop using their assistive technology devices. Only consumers in the African American focus group specifically addressed this, but responses were very similar to those of consumers in all focus groups. The most common reason had to do with devices that were not appropriate. This could occur for a variety of reasons. A few examples mentioned by consumers included the following:

“I feel that I use the cane more than the walker in the house. It’s hard pushing it on the rug.”

“Sometimes I can’t use the scooter because it’s so big. It’s really heavy and it won’t fit in the car. I take the chair.”

These consumers have indicated that the size and type of the equipment has an impact on its use. If it is too larger or difficult to use people stop using it.

“Once they made a brace for me, but I could never find a shoe to fit over it. You know, a size 8 for one foot and 10 for the other. So I never used it.... It’s just sitting there in the closet.”

The appropriate fit is also important. If there is a poor fit there can be pain or injury due to the rubbing or pressure. In addition, if something does not work with other devices then it could be abandoned.

Consumers may also abandon a device because it is no longer needed. Perhaps the equipment was prescribed after a surgery and was used for healing and rehabilitation only. After that time period is complete, the consumer may be able to function without it.

Unique Barriers to AT Use

While focus group consumers from ethnic minority backgrounds did report using some assistive technology, they also experienced barriers. Some of these were unique to certain community members, others were shared by all four communities. A lack of information by these communities was reported as huge barrier. Information about assistive technology does not always reach these communities, so people are left unsure what to do.

“Education. We are not aware of [AT]. People in the Black community are UN-educated on what is available.”

“I noticed that there is very little [information in the Asian American community].”

While the barrier of the lack of information was not unique to these four communities, it was compounded by other factors such as language, attitude toward disability and other cultural issues.

Consumers in the Latino and Asian American focus groups cited language as barrier to accessing information on AT and AT-related services. Even when information is available in languages other than English, it is not always offered to the consumer.

“The problem is that I feel like they tell me they are going to help and nothing happens...Especially when information is given to consumers in English and the places don’t speak Spanish...most of the folks don’t have anyone to translate, so they kinda stay in the same situation.”

Often medical personnel and other service providers do not speak the language of the consumer. Sometimes, with no other means to communicate, children are forced to act as interpreters for their adult family members. Young children often are not mature or experienced enough to handle a potentially complex conversation between an adult family member and their service provider. There may be unfamiliar terms and concepts that do not directly translate between the two languages (Reed & Doe, 2003). Without accessible and readily available information, these consumers are at a loss. The language barrier thus feeds back into the problem of the lack of information previously identified by these populations.

Consumers in the American Indian focus group lived in a rural area of California. The geographical location of these consumers lends its own set of barriers to the access of AT, information and services, including transportation and access to general and long distance telephone service (Sanderson & Yazzie-King, 2001). In the CR4AT focus groups, consumers reported these as huge problems. Marginality or isolation, issues faced by many participants in the American Indian focus group, can become barriers to accessing AT that should otherwise be available to all.

“People miss doctor’s appointments and referrals because rides fall through. People who qualify for services don’t get services because they can’t get to [the city] and that’s where most of the services are. Like people who qualify for [DOR] and people who qualify for Social Security. They don’t get it. Can’t make it to the appointments and telephones...a lot of people up here don’t have phones because the rates are more expensive out here.”

In the rural communities where some American Indian participants lived, low-

income levels were also a problem. Consumers reported having trouble trying to live on minimum wage and part-time employment. Attempting to access services and AT can become almost a luxury to rural consumers with little to no access to transportation or telephone services.

People were hesitant to seek services because of a fear and distrust of those outside their communities. Literacy levels in English were a concern since some equipment operates in English only. Sometimes people were afraid to ask for help because of their immigration status. This was a concern for some members of the Latino community.

“With the wheelchairs, a lot of folks are afraid to get stuff or equipment because they think it’s going to affect their immigration status.”

“A lot of times...it is an immigration situation where they aren’t supposed to be here, so they are afraid to get the help...”

People were afraid to get equipment or other assistance because they are not supposed to receive anything from the government while they are seeking American citizenship. Within the American Indian community, consumers are not very trusting because of a history where people come into the community, take and leave.

“...there is a mistrust of people. It takes me a long time to trust people. It’s like people come in and they pull out.”

When people seek services, they do not receive the needed assistance. Now many are hesitant to talk with anyone or try working with anyone else.

Some consumers may be reluctant to accept their disabilities or need for assistive technology. Participants in both the African American and Asian American focus groups discussed this. In an Asian American focus group, a consumer shared the following:

“...I [couldn’t] face my disability [at] first. I work[ed] hard. I didn’t accept it, so I learn[ed] the way...”

If a consumer cannot accept his or her disability, it increases the likelihood he or she will not use AT. There is still great stigma associated with a range of

disabilities and this can affect how people ask for help or identify as having a disability. In the words of an African American focus group participant:

“Some people just don’t want the rest of the world to know that they can’t see, hear, etc., so they just don’t use their devices.”

Consumers in these communities may be aware that devices exist for them, but are unwilling to use them. Some people work hard to keep their disability private. The use of AT devices brings attention to something the person is trying to hide (Smith-Lewis, 1992; as cited in Kemp & Parette, 2000, p.386).

Improvement Strategies For Ethnic Minorities

Focus group participants from ethnic minority backgrounds identified equal access to information and services as the biggest barrier to AT. An Asian American consumer suggested using community representatives as a means to educate diverse populations about disability related services and assistive technology. Using a “go between” could help community members to be more receptive to new information. In another focus group, a Latino consumer wanted to create a group of advocates representing all the consumers who needed information about accessing AT and AT-related services. Members of this group would work together to disseminate the information to community members so people would learn how to access AT. Peer advocates were also desired by consumers from the Native American community.

Asian American consumers expressed a desire to be seen as more than “Asian Americans.” Participants disclosed they did not always see themselves as members of one homogenous group. One Korean American consumer shared how people sometimes mistake him for a Chinese American.

“Sometimes people think I’m Chinese, but I’m not...I have to tell them I am Korean, not Chinese. Do I look Chinese? I’m not Chinese!”

In service delivery, it important to recognize that each community may view itself as a separate group; therefore establishing contacts in each respective community may better serve consumers.

Consumers also discussed problems that needed more systemic solutions. Like the majority of consumers in the other focus groups, consumers

expressed a desire to see both the public and professionals better educated about disability and assistive technology. Consumers are interested in seeing more funding to accomplish this task. Consumers are especially interested in a Medi-cal funding process that is fair and accessible. In one example, an American Indian consumer was not able to receive assistance because of an old car.

“My brother had an accident ten years ago in a motorcycle wreck and he almost died and he tried to get Medi-cal and he has an old car from like the thirties and they used that against him and said he couldn’t get help because of that old raggedy car. I guess they price it as an antique.”

Conclusion

Focus groups can serve as a valuable tool to capture the feelings, emotions and values of participants along with the research data. Unfortunately, CR4AT was not able to gather the desired number of participants from the African American, Asian American/Pacific Islander, and American Indian populations. Staff and researchers were not always successful when attempting collaborations with community members of these populations. Sometimes ethnic communities may be less trusting of outsiders. Even though most of the people conducting the research were people with disabilities, less than half belonged to ethnic minorities. Even with a person from a similar background being a facilitator there is still the difficulty of establishing a connection with the group being included in the research.

During focus groups within each of these populations, consumers commented on the ability to access information from their respective communities. In the Asian American focus group, a consumer suggested using an Asian American community member as a liaison to facilitate collaboration. In the American Indian focus group, one participant said:

“...people may not want to air their stories in front of people they know...too personal.”

One of the African American focus groups was held at an apartment complex for senior citizens and people with disabilities that is affiliated with a church. The moderator of this particular focus group was a member of the church. Participants in this focus group were more open to participating in the project

because “*they take care of their own.*” In each of these cases, trust was an important factor in determining the level of participation by members of the Asian American, American Indian and African American communities. To address this shortcoming, CR4AT is supplementing this information with data collected from key informants within each of the respective communities. As it has been said before, working with underserved populations requires more time, both in recruiting participants and in conducting research. Eventually mainstream researchers will learn that to adequately address the issues of people who have been excluded, they need to commit more time and resources.

Meetings with consumers from these diverse populations confirms that assistive technology can be and is beneficial to people from ethnic backgrounds, but work still needs to be done to bring the information, technology and services into these communities. While cultural issues do play a role for many, the biggest barrier for all four ethnic communities is access. Many of the other problems, including language and transportation, come back to this main issue. Steps must be taken to reduce the multiple barriers to information and services before members of these populations can experience all of the benefits available to them.

Deaf and Disabled Telecommunications Program Macro AT Success Story

One of the most important and well-known success stories for funding and providing technology is the Deaf and Disabled Telecommunications Program. The California Communications Access Foundation (contracted by the California Public Utilities Commission to operate and manage the DDTP) has been involved with this program for many years and has a large number of consumers. The original legislation mandating the distribution of TTYs was passed in 1979 (SB 597), and the equipment first began to be distributed in 1981. Additional specialized equipment and the California Relay Service (CRS) were later added.

On average, DDTP distributes 130,000 to 150,000 pieces of equipment per year. Since many consumers receive multiple pieces of equipment, this number equates to about 75,000 to 100,000 consumers served per year. Not all of these are new consumers to the program. Many of these consumers received equipment from the program in the past and exchange or upgrade their equipment. It is also important to note that many people need repairs for existing equipment and often the process involves handing back in a malfunctioning device and receiving a replacement.

If a consumer's equipment breaks or malfunctions, the consumer contacts the call center at 1-800-806-1191 (voice) or 1-800-806-4474 (TTY). There are also contact numbers in Spanish. The distribution center sends a new piece of equipment to the consumer, and a box is sent for the consumer to return their broken equipment. UPS returns to the customer's home and picks up the broken equipment.

One of the reasons this program is so successful is that there is no charge at all to the consumer. Many people with disabilities would not normally be able to afford the costs of assistive technology. This program spreads the cost among millions of residents so that no one person has to pay any significant cost. The program is paid for through a small surcharge that appears on all telephone bills in California. This surcharge is assessed on cellular and wireless services, as well as on landline telephone service. The surcharge is collected by all telephone companies in California and remitted to the California Public Utilities Commission (CPUC). The CPUC deposits these funds in the State Treasury. The surcharge is currently set at .047% of all

intrastate charges, and it can be adjusted annually by the CPUC, depending on the need for funds.

Another part of the success is the way the agency has included consumers and people with disabilities as part of the service delivery and operation of the program. They continually search for qualified deaf and disabled candidates to fill open positions at the DDTP. Because they serve people with many different disabilities, all employees have knowledge of and sensitivity to people with disabilities. Deaf and disabled people also serve in key management positions. At the 7 Service Centers statewide, any customer can be served in American Sign Language (ASL), and each Service Center also provides service in at least one foreign language, such as Spanish or Armenian. Also, several of the Outreach Specialists and Field Advisors are deaf and provide their services and presentations in ASL.

The DDTP model of service delivery was developed with substantial consumer input. The program is assisted by three advisory committees whose voting members are all consumers who use the equipment and services provided by the DDTP and who represent large constituencies of program users. Program features such as no age or income restrictions to receiving equipment and a policy to repair or replace all equipment for consumers were designed to enable the program to be responsive to consumer's needs and to make it as easy as possible for consumers to access our program. The program also operates on the concept of functional equivalence. Shelley Bergum, Chief Executive Officer, reported, "Our goal is to make accessing telephone service for the deaf and people with disabilities functionally equivalent to the way people without disabilities access their telephone service. We are fortunate here in California to have a strong and stable funding mechanism that allows our program the funds it needs to implement these important goals."

She also explained how the committees work for the program.

"Our three advisory committees still play an important role in the program. These committees are the Telecommunications Access for the Deaf and Disabled Administrative Committee (TADDAC), the California Relay Service Advisory Committee (CRSAC), and the Equipment Program Advisory Committee (EPAC). Because the members of these committees are consumers who use our program equipment and services, they continually advise the program and the CPUC on the changing needs of their constituents, and they ensure that program policies and procedures keep the

program easy to use.”

The success of this program shows that it is possible to design and deliver services at a state level to provide assistive technology to consumers. California is a huge service area but this service is still able to reach people in rural or remote areas of California. They have 12 Outreach Specialists statewide who provide information about our program through presentations to consumer groups, civic and educational groups, state, local and federal government offices, etc. The Outreach Specialists also sponsor booths at conferences, conventions, and exhibits. Each Outreach Specialist is assigned a specific geographic territory so that the entire state is covered. Staff do not go to the remote and rural areas as often as they would like, but DDTP does get requests from all parts of the state for outreach presentations, and all requests are filled.

There are also 13 Field Advisors who deliver equipment to customers in their homes to assist them with set-up and training. The Field Advisors visit customers anywhere in the state where a home visit is required. Typically, customer visits are scheduled within 1 to 2 weeks of a request, even for customers living in remote areas.

Contributor and Contact: Shelley Bergum
CEO California Communications Access Foundation (contracted by the CPUC to operate and manage the DDTP)

Shelley Bergum
Contract Manager
Deaf and Disabled Telecommunications Program
505 14th Street, Suite 400
Oakland, CA. 94612
510-302-1100 (voice) 510-302-1101 (TTY)
sbergum@ddtp.org
www.ddtp.org

Got Money?

AT & Funding

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

Background

The Community Research for Assistive Technology (CR4AT) project asked questions about experiences with assistive technology (AT) from every group interviewed. One of the most important topics discussed was how equipment or devices were acquired and funded. Participants were asked how they acquired their assistive technology as well as questions about repairs and problems associated with the system. Although the overall results seem pretty dismal, there is hope. Some people have found their way through the maze of requirements, eligibility, and application forms to get what they really need. Although these people are the “lucky ones” many more continue to struggle without the AT they need, however, it does give us direction to consider alternatives to the current system.

Among the themes brought out by the focus group statements were: struggle, repairs, coverage, training, communication, and cost. For only a very small portion of the population we spoke with (and presumably California in general), cost was not a problem. For people with personal wealth or with extremely good health care insurance, equipment was relatively easy to get, but this did not erase the other problems experienced. This chapter will discuss the most frequently raised issues regarding funding and put them into context.

Because this project is looking at issues through an ecological lens, this chapter will also look from the policy level to the individual level. We know that AT can enable and empower people with disabilities to live, work, learn, and participate in society. We know much less about the exact nature of how this empowerment works and what in the system of AT works best. These are the stories told by people trying to get assistive technology. These are the narratives that tell “how it works.”

Struggle: Fighting for Our Rights

Not everyone knows this, but the Rehabilitation Act, the Americans With

Disabilities Act, the Individuals with Disabilities Education Act, and the more recent Assistive Technology Act are all legislative signals that people with disabilities have the right to technology. If the legislators and courts agree that with appropriate equipment and technology people with disabilities are more able to live their lives independently and with dignity, then getting technology should not be so difficult. But the fact is it seems that the system to acquire equipment is so difficult that many people live without life-altering equipment.

Part of the struggle is in waiting. That is, a person may already be deemed eligible and may even know the equipment required, but the time it takes between asking for the equipment to receiving it is over 3 months. In some cases, such as an adapted van, the wait can be 3 years. The struggle then begins by phoning, writing, e-mailing and going in person to ask about the device and why it is taking so long. Clearly there is a process but it is a slow one; there are waiting lists and too much paperwork to complete to even start the processes involved. The fight is a difficult one too, because while you are arguing for your important devices you are living without them. So communication is harder, mobility might be nearly impossible, and health difficulties (because of lack of equipment) might make getting to appointments and doing the needed advocacy difficult, at best.

“Some of the personnel responsible for some of those things just don’t have a clue of how difficult and hard things can be; sometimes just getting the equipment and the things that you need is a full time job.”

This leads right into the systemic problems in the processes—whether through a health maintenance organization (HMO) or a California Department of Rehabilitation (DOR) process, there is often a very specific equipment requisition process that depersonalizes the individual and makes the person wait (unnecessarily) for their needed devices. The paperwork alone could provide work for three or four people and makes it very difficult for those without advocates or literacy to jump through the hoops. Paperwork was mentioned in a number of our focus groups, especially among the people with low literacy or difficulty filling out forms.

The overarching sentiment that was apparent in all focus groups CR4AT conducted, regardless of topic, was the fact that funding was a barrier. Participants reported over and over again that they had to “fight the system” or battle the funder. This reliance on “others” to provide for them also reproduces

and reinforces inequality and dependence instead of independence. Consumers relayed they felt as if agencies that fund AT had intentionally set up a convoluted system with roadblocks at every juncture.

“If you need something that improves your life, why do you have to argue with insurance to get it? Ultimately, it comes down to finding the item and fighting with insurance to pay for it. They look at the bottom dollar and not the quality of life!”

“And they turn you down a couple of times, just to make sure that you really want it or need it.”

There exists a nearly universal experience of frustration and exasperation with the third-party-payer system of AT. One specific problem is that paperwork is not always kept on file for new requests so the assessment process must be gone through in entirety every time for each new piece of AT. Some consumers have resorted to appeals and legal action to get equipment. This is the more formal type of struggle. At the individual level, sometimes the physician recommends or prescribes a device but the funder will not approve it. This probably should be taken up by the medical profession as an insult to their expertise, but the consumers interviewed want to move away from the medical model, particularly the one that gives all the decision-making to professionals. It is also complicated when the insurance company who is denying the request employs the referring physician. The main concern is that the range of funders provides an unfair and uneven access to equipment across the diverse array of consumers. Seniors and veterans have different access than children or students, and people insured under health maintenance organizations are covered less than poorer people on Medi-Cal.

In addition to the struggle once the process is underway, there is a more political struggle on the obligation of the state to provide equipment to various levels. Does AT allow you to be just functional, in your own home, or can it allow you to work, to be a parent, to go to school? If insurance does cover basic life activities, what about recreational, spiritual, or other needs that are personally important but may not be medically necessary?

“I needed grab bars and hand rails more than ever after the baby was born and I never pushed myself to get one, because I would just think, ‘Well, I can get by,’ because I needed other things. But I really needed them, and when I was able to afford them I got some

that I feel now are unsafe if I or the baby fell into it. It's got to come down, but those are things that I had to have, things that the doctor prescribed time and time again; the insurance is never supportive of it."

We asked consumers how they got their equipment, how they found out about it, which agency paid for it, and how they learned to use it. We had a range of answers. For the most part many of the participants paid for devices themselves. Devices that are considered durable medical equipment, wheelchairs, glucose monitors, ventilators, and the like, were most commonly paid for by Medicare, Medi-Cal and other health care agencies.

Funding Frustration

"If you can find the money, I think it's there. But the bureaucracy is so complex that a lot of consumers just give up."

Frustration was a common theme amongst all focus group participants when funding the AT they needed. Consumers are discouraged from procuring AT they need. Many feel that there is not enough information available to consumers to make the choices they need, to find the AT they need, or to locate funding to pay for the devices. Also, consumers almost universally felt that the agencies that serve people with disabilities do not have the necessary compassion or capability to properly meet the needs of people with disabilities. Those in control of funding are most often not people with disabilities and even the most assertive consumers have difficulties advocating for their equipment.

"The funding is always hard. The particular frustrations—our system would lead you to believe we can buy AT for kids to use at home, but they can't take it to school. Schools lead you to believe kids can use it at school, but can't take it home or to another school. That has been the practice. The standard thinking in the industry is we want to put things in nice little organized packages. We expect California Children's Services or schools to buy AT, and then we argue about use, function, or we don't buy stuff for education or medical—it has to relate only to certain disabilities. If a piece of AT is really going to be effective in helping, then get it for the individual. Get it quickly, having the individual accrue the benefits of the device, and each of us pay share of cost. It's a

bureaucratic barrier we hide behind, 'we' being all the funders for AT. Funds are limited, but we could take them and use the money smartly."

The majority of the focus group participants had a difficult time getting the AT they needed. While they were waiting to get devices approved for funding, their daily lives were greatly impacted. It was repeated numerous times in all of the focus groups that people ran into barriers when trying to get their devices. Either they were denied AT and had to appeal multiple times, the paperwork was missing pertinent information, the agencies had overpaid for services and wanted their money back, or agencies just flat out denied needed devices because it was not on the "approved list" of devices; that is, it did not meet the medical model version of functionality, although the device could have greatly increased independent living outcomes. Part of the difficulty is that lists are created and new technology is not added to these lists, and often the best technology is expensive and thus beyond the means of average individuals to buy it.

"I think that the people in the offices, like Social Security, I think they have to stop censoring their money. You know like, have a little more compassion about what they are doing or sensitivity about what they are dealing with and who they are dealing with and not break our stamina. Like every time I go into it, it seems like you have to prove yourself to them and that you have stamina."

If It's Broke It Ain't Working

One of the questions we asked focus group participants was about repairs. We asked this question because our initial literature review leads us to understand that sometimes getting the original equipment is only the beginning of the battle. The equipment—electronic, computerized or mechanical—has maintenance needs. The same piece of equipment that was approved and funded might need repair, changes, or even temporary replacement. The stories we heard spoke of long waits for repairs, many arbitrary rules about when and if something could be repaired, as well as difficulties with vendors and service providers in fixing much-needed equipment. Taking away devices that help a person communicate, that give mobility to a disabled person, or that allow a blind person to use the Internet is not just a matter of inconvenience. Living without the important assistive technology can be life altering—it may

even impact the way that person participates in their community. So policies around the provision of replacement, servicing equipment, and funding or doing repairs have a direct impact at the individual level.

There were problems about warranties, what was covered, and how replacement equipment wasn't available. Regular maintenance was a problem for many people who for physical reasons (i.e. disability) could not conduct their own maintenance. In addition, it was often difficult to get simple repairs done without a long wait and expensive process. One consumer went to bicycle stores to fix his wheelchair because it was so affordable. In addition, the AT that breaks down might not be replaced for a certain number of years due to the "cap" of cost and time. This means it might be a 3-year wait for a new wheelchair even though the person is eligible; they still have to wait because of an arbitrary time cap. Repairs are a major issue in the disability community especially for highly technical and essential AT.

"I had a portable bath chair and it broke. I requested another one and they denied it because they would only give one every 7 years. So I went back to my house unable to use the toilet. So I had to buy myself a new chair."

Are You Covered?

From our literature review and focus group investigation it seems that it is well known that funding AT devices can be an arduous and time-consuming process. The two big issues seem to be coverage of the individual for funding at all, and then coverage for the particular device. Some agencies will fund a manual wheelchair but not a power wheelchair and others will fund someone who is 21 years old but not someone who is 18 years old. The issue of coverage was raised many times as part of the ongoing struggle to attain the equipment that is necessary for living a full life.

Based on our research, we found that a consumer must know the "ins and outs" of a funding agency's requirements before getting the device approved, and then delivered for use. Because every agency who funds AT has its own set of eligibility requirements, including a list of devices that will and will not be funded, and an ingrained system that seems to work against the consumer, many people give up completely and exist with substandard devices, or none at all.

“[They] are constantly changing the rules and they change you from person to person; it’s ‘I’ll pay, you pay,’ back and forth.”

There are three key factors in the development of eligibility or coverage issues. First is the significance of the medical model in the way that technology is funded. Second is the timeline, or history in how technology has burgeoned and the legislation is barely keeping up. Third is the way that consumer activists and Independent Living Centers and other agencies are being used as brokers to work with the funders of AT. Overall there is a real lack of knowledge about what is and is not covered, by whom and how. This lack of knowledge, addressed later in this book in the Information and Education chapter, is a key to the solutions needed in the system.

Necessity Is the Mother of Aggravation

Many AT devices are only funded or made available if they are a “medical necessity” according to funders and the medical professionals who determine the need. Respondents in the focus groups suggested that the definition of “medical necessity” hindered their options to live completely independently and engage fully in community integration. It was noted that the stringent definitions of Medi-Cal and Medicare prohibited people with disabilities from full participation. In addition, it was found that the strict definitions could actually pose a safety hazard as well.

“I think I would make it easier for people to get the equipment that they need. Medi-Cal and Medicare are famous for ‘medical necessities;’ they try to make it as small as possible and things get overlooked. Well, what about a wheelchair ramp—it is not covered as a necessity but I didn’t know you were supposed to stay in the house 24/7, isn’t it a necessity to get outside once and a while? I would say it is a safety hazard because what if you had a problem in the house and you had to get out? Open up the necessities to things that people need not just because it is a wheelchair or medication; give us access to everything, vendors, medications, all that. I would want to redefine these terms!”

The agencies that fund AT have “maintained eligibility criteria that are based upon the medical model definition of disability [in which] medical professionals must certify that an applicant has a disability. The eligibility criteria ignore the

fact that environmental barriers frequently limit the full and equal participation of people with disabilities in employment and their community” (Council of Canadians with Disabilities, 2000). The deep-seated medical model mentality embedded in these agencies does not consider that persons with disabilities must leave their homes to participate actively in work and in their communities. “It does not engage in positive and meaningful ways with those who have disabilities, so that they are not socially ostracized and so become a barrier to their social participation” (Duchan, 2001).

“You mention independence, and I think that is part of the factor you need to bring into the justification for assistive technology that you are looking for. You need to stress the fact that it will allow you to maintain your independence.”

“I would not have the requirement about you being able to walk in your own house to get a power wheelchair.”

For most of the medical model perspective, there is a deficit in the body that could be corrected or mediated by a device. The simplest of these is perhaps a prosthetic device, a false leg, for example. But there are many complicated issues about what is covered. There are issues of aesthetics and function and what will be covered is usually what allows the person to walk, not what looks the best or what might allow the person to “pass” as non-disabled. Certainly false legs for swimming or athletics are not covered and even getting myoelectric devices that allow far greater functionality are restricted from basic funding. They may be funded under a research and development project or by an industry program, but often the basic funders take into account only the “medical necessity” for a basic device.

Three areas mentioned as a problem include the lack of coverage for temporary and episodic functional difficulties (which is worsened by the length of time it takes for approval), lack of coverage for independent living needs rather than medical needs, and what are considered “luxury” items or components not being covered.

“The tub bench I use is a luxury item according to the government [state]. It allows me to sit in the shower and not on the floor.”

Participants reflected that, in their mind, the difference between necessity and convenience means nothing if it impacts their independence. People would like

to see this reflected when applying to agencies that fund AT. In addition, it was found that funding agencies oftentimes don't find a person "disabled enough." There is an onslaught of paperwork required, and an individual approach is used instead of a holistic approach of funding AT. Another issue mentioned was the constant requirement to prove you are still disabled, still poor, or still not working to maintain eligibility even if the equipment was meant to mediate your disability.

"I have a brain injury and I am also dyslexic. I was told by insurance companies and doctors that I was not disabled enough to get funding, so I paid for my own AT devices out of pocket with NO help from DOR. Medicare has paid for some of my equipment but going through them is a hassle too, because you have to go through so much paperwork; it can be frustrating."

Perhaps the need is now to stop viewing AT as "special" and people who need AT as "special." Just like a microwave or a dishwasher is now pretty standard for most people, hearing aids, wheelchairs and Braille 'n Speaks⁵ should become standard for people with disabilities. Funders have absolute discretion in what they will or will not allow, and because of the complex system there is very little recourse. Consumers mentioned they felt they get by with less and less effective AT because it costs less for the funder. There are a considerable number of unmet needs in the community and the research has demonstrated that the frustration is building.

The definition of "medical necessity" encompassing only the individual functional capabilities also posed a hindrance to those with disabilities that are parents. When meeting with parents with disabilities, the results showed further insight into problems of parents with disabilities. The biggest issue was adaptable equipment to take care of their children. When attempting to secure funding for AT devices, parents reported that insurance companies rarely thought of their parenting needs. Insurance companies looked only at the individual. This limited access to technology that would assist parents with disabilities to independently care for their own children. "Parenting," it seems, is not considered an appropriate role for people with disabilities, at least by the funders of equipment and AT.

⁵ A portable note-taking device that allows the user to input information in Braille with a keyboard, and plays information back using a speech synthesizer. For more information, see the Web site at: <http://www.freedomscientific.com>.

“When your insurance will cover something, they don’t take into account what you need for parenting. They only look at you and that is very difficult because even when there might be a solution you don’t have access to it.”

Impact of Technology Change and Legislation

One of the issues that are raised about coverage is whether or not the legislation covers specific devices. But everyday there is a new piece of equipment brought onto the market. There are breakthroughs in technology that could enable employment, health improvements, parenting and education, which did not exist when the legislation was written. This means that the newer technology tends to not be on the “list” of the legislated funders. The equipment that occupational therapists and physicians know about is the older, more tried-and-true versions of devices. The new devices are often displayed at expos and conferences that state-funded agency staff members do not attend.

Legislation that was written under one premise—that disabled people deserve the right to live in their own homes—might not take into account changes in the economy and the overall nature of employment that now allow that same person to enter the work force, but with new equipment. Where we might have accepted independent living and community inclusion 20 years ago, now we are demanding access to education and jobs. It might be that by getting equipment to let you live safely in your home you deny yourself the opportunity to leave your home to seek employment. Mention was made that age discrimination and degree of disability was taken into account by funders deciding if you were going to get equipment.

“You have to be extremely poor to get Medi-Cal, so what do the rest of us do? I don’t have money for medications, I can’t pay all of that money.”

Income levels were mentioned as conditions used to determine coverage. Time and time again, the respondents stated problems with Medi-Cal and Medicare eligibility requirements. There were the instances of whether one was “poor enough” or not to be eligible to receive services or devices, or whether one had contributed enough to the Medicare system through employment. Being the wrong age was also a factor in determining eligibility, as well as was the degree of disability. In regards to degree of disability, people responded many times that they were not seen as “disabled enough” to

qualify for services, although they had a verifiable disability.

Coverage also varies from funder to funder which makes the “struggle” even more like a maze, especially since consumers might not realize that by getting a device from one source they restrict eligibility from another. We found from our research that the most frequently used sources of funding were self-payment, Medi-Cal, Medicare, California Department of Rehabilitation, and health maintenance organizations, like Kaiser Permanente.

Every imaginable funding source was named in the focus groups. The top sources of funding AT were persons with disabilities paying out of their own pocket for devices they needed. Medi-Cal, Medicare and Kaiser were responsible for many durable medical equipment devices. Also included was the California Department of Rehabilitation, specifically the Vocational Rehabilitation section that aided those who needed AT in employment.

Although another section of this chapter deals with cost (which is tied to all the other issues), one of the main funding sources for equipment was the individual. This deals with the issue of coverage in a very particular way. Informed consumers who had knowledge of what they needed were able to buy it themselves without the hoops and mazes of the funding agencies. This was most common, of course, for the lower-cost items, but it is important to discuss that many people with disabilities are using their own money to pay for equipment that is not covered (but should be) by agencies.

“I didn’t have insurance or anything, so we bought the cane; the inhalation machine and the oxygen we had to pay for ourselves. The inhalation machine was over \$100 and the oxygen’s original cost for the tank was over \$100. The cost of oxygen is only \$12 a tank for refills, but all of that came out of our pockets.”

Self-payment for AT devices was one of the top means persons with disabilities used to obtain their equipment. Paying for the devices out of one’s own pocket provides the consumer with more choices in the decision-making process and allows them to obtain the necessary devices in a timelier manner. However, incurring the debt of paying for devices out of pocket is not an option for many, and it also creates a problem when one lives on a limited income and cannot afford the devices one needs, and so goes without. This also is discussed under the issue of cost later in this chapter.

“I used any credit card anybody would approve me for. I am now paying for it for the next 5 years and when these creditors would call and say, ‘well I see that you have been shopping at Nordstrom,’ I started going to get gift certificates, cash them and use the money to go and do whatever I need to do.”

For many of the respondents in the focus groups, the California Department of Rehabilitation (DOR) assisted in funding most of their equipment needs for employment. Devices funded by DOR ranged from less than \$600 to over \$50,000. Types of devices purchased by Department of Rehabilitation included computer hardware and software adaptations, such as large monitor, screen-reading programs, and the computers themselves. Modified vehicles were funded through DOR, as well as hearing aids, and various low vision/blind devices such as Braillewriters. It was also relayed that DOR provided education opportunities for many of the focus group participants. One participant recounted a positive experience in dealing with DOR; DOR provided the consumer with a note taker and computer, and arranged for the consumer to take a computer training course in preparation for employment.

The overall experience with DOR was mixed. For many, they had no problems receiving services or obtaining devices through the program. On average it took about six months to receive the needed AT. For others, however, it took years to get equipment funded through the program. One person relayed that he or she “would probably die before the van would be approved” from DOR. A few other participants relayed that it took 3 to 5 years to receive equipment from DOR.

While the focus group responses were generally in favor of DOR services, several issues arose surrounding the State Department’s modus operandi. It was reported over and over again that DOR provided the equipment, but provided no training on the equipment. One person still had their computer sitting in a box waiting to be put together. Other concerns that arose out of the focus groups were that DOR would purchase the equipment, but there was no warranty or maintenance agreement that came with the equipment.

Several respondents stated that when working with the DOR they felt that their opinions and choices were not taken into account during the process of obtaining the needed services and devices for employment.

“They call the shots. They tell you where you can go, they tell you

what shop to go into, they have total control over the process.”

Professional training for DOR counselors was mentioned as well. Because the counselors have large caseloads with clients who have a variety of disabilities and needs, the counselors are not able to keep up with the various types of AT available to their clients. This creates a chasm between what’s available and what’s provided—oftentimes leaving the consumer with a less-than-desirable device that does not meet their needs.

“I think the problem with DOR is that they have persons there dealing with very wide differences...now she’s scrambling for the last 2 years trying to bring her knowledge up to snuff so that she knows what devices are out there, and what they have to offer; DOR aren’t even teaching their own staff, so how can they help you?”

Others with hidden disabilities such as learning disabilities or traumatic brain injury stated that DOR would not even accept them as clients, although there was a need for AT in employment. However, when checking with the DOR (2003) Frequently Asked Questions posted on their website it states that they “serve people with all types and categories of disability.”

“I would throw requirements on Rehab [DOR], so that everyone gets help and everyone gets help in a timely manner.”

Community Support for Technology Acquisition

In response to the difficulty in acquiring equipment through the federal or state government, many innovative and successful alternatives have been developed. The news is not all bad. There are some ways to get equipment with limited frustration. The coverage issue can be mediated if the community or organization is aware of the needs of the consumer and is in a better position to either provide it or advocate for it. In California, the state telephone program charges a fraction of a dollar for each subscriber each month to gain a pool of money that is used to deliver services through the Deaf and Disabled Telecommunications Program (DDTP). This program provides free accessible equipment to people who are eligible. The coverage issue seems relatively clear for DDTP. You must live in California, have a physician certify your disability and need, and must benefit from one of the many devices available through the program. This coverage is quite broad and covers everything from

TTY and signaling devices to hands-free telephones for physically disabled people. Part of the flexibility here is that the funding is pooled from all across California and there is an attitude of privilege for those already paying to use the phone system. Also interesting to note is that the DDTP hires a lot of deaf and disabled people to work in their stores and to help train consumers in use of the equipment provided out of DDTP funding.

“I just called the telephone company and told them I needed some type of device and they sent me a high amplified telephone and a device that I could use at work that I attach to the receiver of the phone and from that I can amplify the sound.”

The less bureaucratic or complex the funding source, the broader the coverage seemed to be. Non-profit agencies such as Easter Seals, Independent Living Centers and other community agencies were most often named in donating devices people needed. Other agencies included the Veteran’s Administration, employers, California Children’s Services, Regional Centers, COBRA, schools for those in grades K-12 and long-term care or hospice. Health maintenance organizations (HMOs), preferred provider organizations (PPOs), and other private health insurances were also named.

Training (Or Lack Thereof): A Problem for Professionals and Consumers

One of the benefits of a focus group is that people come together to discuss common issues and learn from each other. In many focus groups someone mentioned a process or device that worked for him or her that someone else in the group did not know about. The key to this seemed to be that training was not provided to professionals or consumers on the AT issue.

Training was needed on how to fit devices to individuals and how individuals would use the devices. This is an unmet need in the process of funding because often the device is paid for but training on how to use it is not. Professionals—vendors, occupational therapists or other specialists—need to be trained and up-to-date on the equipment with which they are provided or the consumer has no chance at efficient use of the device. The training is often only a few hours long but sometimes could take as long as two weeks. Several people with Braille note takers were able to take notes but had no training on how to print and therefore never used this essential function of the device.

There are definitely two parts to the training issue; one is making funding available for the human time spent in training the consumer and another is in making training itself a more connected part of the AT acquisition process. Annually at the California State University at Northridge there is a certificate offered on assistive technology and now more people have been trained (and updated) on the issues. But these people are rarely the decision makers at the funding agencies and even more rarely the consumers themselves. Training on AT devices needs to be provided to health professionals and vendors as well as consumers. The consumers need mostly to be trained on their own devices, but it would benefit them to learn also about devices they do not yet use or do not yet need. Professionals, on the other hand, have an obligation to be familiar with a huge range of options and equipment as well as how to use them. Funding needs to be available to train the professionals, for the professionals to train the consumers, and for the consumers to learn about AT.

“The manufacturer sells it to a dealer, and the dealer does not want to spend the proper time with the customer. And the customer is the one who really needs the consideration and like you say, you’ve got to really advocate for yourself. Because time is money to the dealers and they don’t want to spend the time and that’s where the fit comes in.”

(Mis)Communication

Communication is a key to both bad service and effective service. It is tied to funding at many levels. Our focus group research indicates that you need to have a lot of information and be a skilled self-advocate to really get what you need in the most effective manner. Doctors, unfortunately, rarely know more about AT than wheelchairs, grab bars and bath chairs. The physicians today do not know the technology available, yet the professionals are major gatekeepers in the process of getting technology. Often the meeting between the doctor and the consumer/patient is inadequate for the doctor to understand and prescribe the correct device. Funders will deny requests if it is unclear to them the type or purpose of the device. This causes further delays and often starts the cycle of frustration and disappointment discussed throughout this chapter. Because doctors often answer to the insurers there is a pressure to not prescribe highly expensive devices even when these might be the most appropriate, or even medically necessary. If it is difficult to communicate to a doctor what is necessary, it is significantly more difficult if the device is not medically necessary but important to independence. Along with the communication

problems between the doctor and consumer, there needs to be better communication between and among the doctors and other health professionals and the vendors and service providers. The long road to getting AT is complicated by the miscommunication and lack of communication among professionals.

"I did all the research myself. So I wrote the letter myself justifying the equipment and I sent it in to him [the doctor]. He signed it, and sent it off to the vendor. They looked at it and said, 'Yeah, this is promising.' And then sent back, I believe, the Certificate of Medical Necessity. It really needs to be sent by the doctor's office. They don't really like to get the individual involved. But the doctor signed the letter, so there wasn't going to be any problem. It was like he wrote it. And being that the doctor's office was affiliated with Rehab then it was not a problem. I understand that, in general, doctors who don't get involved with this very heavily, who don't like to fill out these forms and a lot of time will tell people, 'I'm not going to take the time to fill out the form.' Yet, if they don't fill out the form, you're lost because you can't get anything reimbursed."

Communication about AT needs to look at what types of AT are available under the current system—which changes monthly. In addition to the types of AT, the different types of funders need to be well understood. Even though this research was conducted by Independent Living Centers in California, almost every focus group experienced a sharing of information resulting from a lack of communication. Someone at every focus group learned something they did not know because of previous poor communication. Consumers are not aware about what funders do or do not cover and often have difficulty communicating their needs.

Consumers who were most aware explained to others about the different agencies and what was covered. This type of peer education and communication must be facilitated so that the most isolated people do not remain poorly served. People in rural areas and people with language or communication barriers were among the least well informed. Communication between the consumers and the Independent Living Centers' (ILCs) assistive technology advocates also need to improve, as many focus group participants did not even know there was trained staff at the ILCs who could help them. Although some consumers communicate through the Internet and learned about devices online in catalogues, a general suggestion was that a library

about AT or a database was needed. Sadly, the AT Network funded by the Assistive Technology Act and administered by the California Foundation for Independent Living Centers (CFILC) actually has a database that many research participants were not aware of. This shows the desperate need for communication.

Outreach is desperately needed for people living in rural areas, on Indian reservations, in institutions, and in underserved minority populations. If people attending the focus groups were uninformed then there are many more barriers and communication gaps among the people who did not attend. Sharing information and communicating about AT needs to be part of the system so that effective advocacy can take place. The knowledge about AT and about the funding system is one of the primary tools in increasing success in getting equipment funded. The success stories shared in the focus groups were by well-informed, well-connected consumers who knew their way around the system. Some had to legally appeal, some did not, but they all had to advocate. The ILCs, family members, and social workers were also named as partners in the advocacy process but the key is knowledge and using it. Wise consumers shared with us the key to networking is knowing who to contact and having a personal relationship with people at the funding agency as well as vendors and professionals.

“I have such a good relationship with my doctor that I don’t feel embarrassed anymore to ask for the things I need.”

Communication with service providers is a “make it or break it” process. It is when the need is clear, the device is selected and the eligibility is understood that successful AT funding occurs. Unfortunately, too often there is a mismatch of equipment due to poor communication between the consumer and service provider, or the doctor and the funder or even the vendor and the funder. Communication includes clear guidelines, phone conversations, Internet e-mail, and in-person contact. Often there are people working on the same issues all over the state without knowing each other and perhaps even working at odds with each other. Coordination and communication among and between service professionals was a priority mentioned in the focus groups.

Cost of Living (With a Disability)

Research has repeatedly demonstrated that the cost of living for people with disabilities is higher than for people without disabilities. Having to fund your

own devices adds to the cost of living. Medications and some services might be covered by insurance but often the needed technical aids are not. This is why the wealthy or well-insured disabled consumers are able to access equipment on the market and poorer and less-insured people are left without AT. While it is clear that it is more expensive for a disabled consumer to become educated, trained or employed due to extra costs of equipment, services, or support, there is no recognition of this in the funding system for AT.

“Once a disabled person gets out of the home and gets active, it costs three to four times more than a non-disabled person to go and get an education or a trade school and succeed.”

There is also a problem related to the size of the market and the availability of equipment. For the segment of the population growing older, equipment such as canes, bath chairs, walkers, and electric scooters have become much easier to get because the demand is increasing. But for people with very unique situations, or rare disabilities, or even common needs but uncommon configurations, there is great difficulty in finding appropriate equipment. The customization needed is difficult to find and far too expensive for the ordinary consumer to pay for. In many cases the individuals with complex disabilities are also dependent on service providers who have to advocate for them.

In 2001, President George W. Bush passed the New Freedom Initiative, a comprehensive plan to “tear down the barriers facing people with disabilities and preventing them from participating fully in community life” (United States Department of Health and Human Services, 2002). In March of 2002, nine agencies submitted a report outlining a self-evaluation process and barriers to be eliminated to promote the inclusion of people with disabilities in society. Access to technology was a key point within this report, and seen as a fundamental component in enhancing independent living and community integration for persons with disabilities. Specific solutions suggested in this report regarding AT states that, “DOL will work with ED, HHS, the Department of Agriculture and other agencies to coordinate and implement a plan that improves the availability, affordability and accessibility of technology in the school, home and workplace for youth and adults with significant disabilities” (HHS, 2002). Executive Order 13217 that this report was filed under urges “the federal government to assist states and localities to swiftly implement the decision of the United States Supreme Court in *Olmstead v. L.C.*...” Nineteen months after the submission of this report under the New Freedom Initiative, no changes had yet been made on the systemic level of funding AT.

Currently, persons who purchase AT have the option to claim tax deductions. However, it is difficult because neither the “tax forms nor the tax guidelines have the word assistive technology printed on them” (Jeserich, 2003). Additionally, to claim a device as deductible, it must first fit into an already existing IRS category. It must also be proved “that the device extenuates a disability or limitation.” Moreover, if someone else, like Medi-Cal, purchased a device then the device is not deductible, unless the persons paid a share of cost for the device, then only that portion would be deductible. While tax deductions do exist for AT, the process is unclear and vaguely defined for those who would benefit most from the deductions.

All through the focus groups participants mentioned how outrageous the cost of AT was compared to the mainstream consumer market. The examples given included buying devices at Radio Shack and Fry’s Electronics for a fraction of the cost of the medical or AT equipment vendors. This also provides us with some interesting thoughts. If the funders want the costs to be lower, they might want to enter into agreements with the mainstream vendors so that consumers get their equipment faster, with better service and in their communities rather than through a monopoly of medical equipment dealers. There is also an opportunity here for the consumer to advocate for better information among the mass-market vendors because they could be selling more of the devices that are now only available through medical equipment vendors. Many hard of hearing and deaf people found devices that suited them at Radio Shack and people with mobility disabilities said that computer adaptations were available at Fry’s Electronics, accompanied by good return policies and service. Consumers noted that the industry and vendors were making money off the needs of disabled people by “banking” on the funding system paying the higher cost and ignoring the people without funding who could never pay out of pocket the exorbitantly high prices charged for basic equipment.

“I have noticed when researching on the web prices vary a lot among manufacturers for AT versus devices for normal [non-disabled] people.”

The current cost of most AT is too high for people with disabilities to pay out of pocket, as stipulated earlier, with the exception being the minority of consumers who are wealthy enough to pay for the high priced items themselves. Consumers dependent upon the funding mechanisms as they are now often go without. Stories were shared at the focus groups about using social support income to pay for both medication and AT and as a result going

without food. Others could only afford food, and had to go without medications or AT. People shared how they paid for equipment on credit cards with high interest rates and ended up in debt, continually paying off the cost.

“I can’t even afford all of my medication; if I didn’t have a doctor that was so good to me I don’t know what I would do. I’m on seven medications and he gives me five and I only have to come up with two—if he didn’t do that I wouldn’t be able to afford it.”

What Needs to Be Done

One important benefit of focus groups is that you learn from consumers what they want done. In this case, the issue of funding was so crosscutting that there were over 683 individual comments made on the topic across 43 focus groups. There were 10 suggestions that came up most frequently as ways to address the problems discussed so far. The first one was to rearrange the whole funding system including dismantling the current health maintenance organization system which many people felt caused limitations in getting devices. Also mentioned was a chance to try out equipment either in a specific location or by borrowing like a library, before purchasing so that fit, suitability, and training could be addressed.

“Education and awareness; the community should be educated and aware of people with disabilities. Perhaps a library with various AT equipment to be tried out prior to purchasing. Products should be useful and readily available to the public as people age; they will need the same technology. Family members should be educated on other family members’ disabilities to better assist them with taking care of loved ones.”

Of course one suggestion was that the unnecessarily high cost of AT be contained and the basic costs reduced so AT is more affordable for both individuals and the funders. Community members mentioned universal design of systems, buildings and devices to enable more people to use more of the built environment without adaptive devices. This was not suggested instead of assistive technology, but as a strategy that needs to be adopted side-by-side with AT. Another strategy mentioned was the need to change the eligibility and definition of AT to include the urgent need to access communities, not just to live in homes. This addresses specifically the medical model and problem with durable medical equipment which still has the language of “use in home,”

prohibiting many devices from being purchased. Consumers in California have suggested that a national system is needed so that services and equipment are portable and that what is not available from one state can be purchased from another, or even that a better standard be in place so more states are similar in what is available.

“I think the first thing is, all people with disabilities should be provided help without all the red tape I keep hearing about. If they have the things you need someplace and they say they provide these things for you, why do you have to go through so many changes in order to get these things? If you qualify for devices, why should it take two to three years to get to it?”

Collaboration amongst agencies, particularly community and government, was seen as necessary to any major change in the system. And this change could not, and should not, be made without the input and significant contribution of people with disabilities who use AT. Whatever changes are made, the system needs to be easier, not harder, and this means streamlining the decision making and provision of equipment. One suggestion for this was the use of case advocates/managers to ensure that all the parties involved in the process are doing their jobs and that the consumer is not left out of the process.

There is much work to be done in the area of funding. Perhaps more than any other area because it is embedded into each and every topic we examined. We know that consumers have prioritized this as an issue. We also know there are answers, sometimes easy ones, that could be implemented if there was a will. Community members with disabilities have shared their stories with us, as researchers, and now action must be taken. The next phase of this research is a large-scale survey to quantify the need for AT; but the more important step is taking action on what we already know to make things better in the lives of people with disabilities in California.

The More You Know

Information and Education About AT and Disabilities

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

Every focus group identified the need for information and education. It was evident in those groups that talked about employment, health, independent living, those with different ethnic backgrounds, and those with different disabilities. Focus group participants identified many problems. The definition of AT needed to be more mainstream. There was little awareness of different types of AT available. Resources for obtaining information about AT are scattered and unfamiliar to many. The process for obtaining and funding AT is convoluted and presents a large information gap.

The Information Gap

Lack of information has a direct impact on consumers' abilities to effectively access technology. A clear-cut lack of choices, lack of understanding, and lack of knowledge were evident in many of the focus groups. This lack in understanding and knowledge results in many feeling isolated, frustrated, and angry with the system. The lack of needed AT ultimately impacts consumers' health, employment options, and community integration opportunities.

As one participant noted:

“Yeah, but if you're isolated, how will you know? I can't see, I can't read anything, and if I didn't know anybody, how would I find out about these things? After a while, you say, 'Forget it.' You feel so humiliated. Then you think there's something wrong with you; one person gets something but I don't.”

People feel there is a lack of available information and funding. Consumers in the focus groups felt that people don't even know what “AT” means. There are numerous devices available for any disability. However, many are unaware that devices even exist that can enable them function better. A simplified process of providing AT information could help people find the AT they need.

We learned from our focus groups that many people had to research AT

themselves on what they needed because doctors or professionals didn't always provide the necessary information. Although many service providers try to help people try out different devices, such as hearing aids, there are still problems posed with fit and match. Agencies that serve people with disabilities, like the California Department of Rehabilitation (DOR), do not provide magazines or information resources for their consumers to locate AT devices. Consumers complained that AT vendors also don't spend enough time explaining the various options available to someone looking to purchase AT. Consumers related that they were sometimes given a referral to the wrong vendor or for the wrong device.

For those who are aware of funding agencies, such as Medicare or Medi-Cal, the procedure for funding their devices is often unknown to the consumers. It was stated in the focus groups that consumers should know the barriers they may face and how long it takes to get a device funded before heading into the process of procuring AT. It was also noted that the AT system is intimidating to consumers because there is a slow process and a lack of information to obtain AT. This causes many people to give up in obtaining the devices they need.

People are unaware of where they can go to get devices they need. Some communities have multiple vendors from which to obtain AT, while others have one person providing all the AT for that area. Even more commonly, communities may simply lack providers of certain kinds of AT. The Internet has become a great resource to those who have it and know what they are looking for. However, those without Internet access and the ability to shop online must travel inconvenient distances to obtain what they need, or go without.

In addition, consumers find that they are unable to try devices before purchase. Participants felt that they needed to know what they were getting before they purchased an item and were unable to make good purchases because of the lack of "test driving" the AT. In addition, it was suggested that standard price lists be available for AT, so that consumers would be able to comparison shop like one would for any other major purchase one might make.

One participant gave an analogy:

"You don't go into a dress shop and just purchase [a dress], you try it on first to make sure it's a good fit."

(Un)Equal Access to Information?

People need easier access to information about AT. Informational services, such as the AT Network, a program of the California Foundation for Independent Living Centers (CFILC), are known to some, but not to many others. One solution was to have one phone number to call to lay out the problem and receive information. Additionally, it was suggested that more programs on cable TV be made that provide information about AT and what's available.

Language is a barrier, especially when information is not provided in the consumer's native language, such as Spanish. For example, someone who speaks Spanish is given instructions for his or her device in English, thus rendering the AT useless because the consumer cannot read the instructions. Providers of information services via the telephone do not always speak the language of the person needing services. Additionally, required forms at many agencies and service providers are not available in languages the consumer reads or speaks.

Access to information is not equal. It was suggested in the focus groups that computers and the Internet should be made affordable to own for all persons with disabilities. With a computer and Internet access, they would be able to research their needs as well as advocate for themselves. In addition, Internet access provides peer support opportunities for those with disabilities by allowing them to connect with others in similar situations. Also suggested was that a Web site specifically geared towards AT needs to be created so that one can search on one's own. Most participants were not aware that such a Web site, ABLEDATA, actually does exist (<http://www.abledata.com/>). This demonstrates the need for the dissemination of information; consumers are missing out on valuable and needed tools because of a lack of knowledge.

Concerns about consumer rights appeared numerous times throughout the focus groups. Social Security, Department of Rehabilitation, and other agencies need to advise consumers on their rights. Consumers have the right to know what services are available to them through the agencies that serve them. The focus groups often reported that consumers did not know they could access certain services from various agencies. It is important for people with disabilities to appeal decisions as far as they can because often an initial denial can be reversed but consumers are not told they can appeal. Advocates who are especially training in AT are available through most ILCs and can provide

assistance in learning the system. To improve the system, however, the agency officials must be more open in discussing option and rights to appeal so that people are not turned away without alternatives.

Public Education: A Public Responsibility?

Participants in the focus groups felt that a large-scale education campaign needed to occur on a national level to inform and educate the general public about AT and its potential for improving the lives of seniors and persons with disabilities. Though this project only conducted research in California, we have identified issues that demand action on a national scale. Political action was demanded as a necessity to educate the public. Areas identified as requiring further education included disability awareness, sensitivity training, employer education, health awareness, consumer education, community awareness and accessibility, and service provider training.

We received a range of responses in regards to education. The respondents believed that disability needed to be demystified for the general public: non-disabled persons and employers. Once people understand disability rights, education on AT is also needed, including products ranging from expensive, high-end devices to universally designed equipment that is commonly available to all at minimal cost. Participants reported repeatedly that those without disabilities do not understand what a person with a disability goes through, because they have never been told. Participants felt that the non-disabled need to be told what it is like to live day in and day out with a disability. It was suggested that the media, such as television, be involved in educating the public by airing public service announcements showing the cause and effect of AT so that others could get a better grasp of what AT is, and how it benefits the lives of people with disabilities. Videos to increase disability and AT awareness could also be created and distributed nationally.

On the other hand, focus group participants felt that people with disabilities could also use some education. People with disabilities need to educate themselves more to know what's out there and how to get it. They need to be active participants in the AT process.

Can Attitudinal Barriers Be Overcome?

Attitudes among service providers, including funders, vendors, and technicians, need to be improved. Attitude and lack of awareness were seen as

two of the greatest barriers when trying to educate and inform non-disabled persons about AT and disability.

Respondents felt that people with disabilities are treated unfairly and unequally because they are different. Disabilities are commonly viewed as “something wrong.” Those without disabilities do not understand the civil rights of people with disabilities.

Some disabilities are more “acceptable” than others. Age discrimination appeared as a common response. Also, people with hidden disabilities are oftentimes seen as using services they shouldn’t, such as disabled parking and accessible bathroom stalls. Information about invisible and episodic disabilities needs to be included in training for disability awareness.

Are the Professionals Helping?

Many felt that there exists a call for professionals who work with persons with disabilities—the doctors, occupational therapists, audiologists, vendors, and manufacturers to provide more and better information about AT to their consumers. Respondents relayed that they believe professionals are withholding information necessary for persons with disabilities to make informed choices about AT usage.

One respondent relayed her experience with the Department of Rehabilitation:

“Right before I moved back here, I had a Rehab counselor tell me, ‘Did you know that they would have helped you with a computer if you had asked them?’ But they didn’t tell me I was entitled to that. They just kind of said, ‘Do it,’ and expected me to get a job, but didn’t give me a way to do it. So, I was on my own. It’s a big circle.”

Participants in the focus groups felt that there was a lack of sympathy on the providers’ part for the plight of persons with disabilities. It was felt that their knowledge level about the people they are serving—persons with disabilities—was lacking, negatively impacting the types of AT recommended and funded. It was suggested many times that professionals should be made to better understand the daily experiences of a person with a disability. Participants felt that if those who serve them were more aware of the daily trials that a person with a disability must encounter and general disability issues, then coordination of services would vastly improve for persons with disabilities.

As one participant noted:

“Maybe government agencies should be more knowledgeable about disabilities. They are not sympathetic or empathetic, not attuned or knowledgeable of what devices assist people.”

It was found that professional training on AT devices was lacking as well. People would like to receive training on their devices, but it is not always provided. Many people train themselves on their devices, or abandon the devices because they do not know how to use them. Training is not standardized. Ongoing training on adaptive equipment for computers also proves difficult because changes in technology occur so quickly that it may be difficult to keep up.

Why Self-Advocacy Is so Important

Self-advocacy played a major role in the various forms of information and education available to many of the focus group participants. It was also seen that the participants were engaging in various types of peer support because their information needs were not being met by other venues, such as vendors, insurances, and informational resources specifically established to teach others about AT. People with disabilities need to take an active part in educating others about their needs and to advocate for their own AT needs.

Advocacy plays a major role in information dissemination about AT to consumers who were previously unaware of its existence. We found that many of the focus group participants had taken it upon themselves to visit nursing homes, friends, audiologists, public service agencies, and a myriad of other service providers to educate them about the existence and use of AT.

One person's advocacy experience was related:

“What I experienced was I wanted to go out and tell people about this and so I went to these retirement homes and began talking to people, and they were all staying home because they didn't know these devices were out there. That's why I've taken on this project to try and inform people that they don't have to stay home, they can do anything they want to do. That there are devices out there that will enable them to do it.”

Others were connecting with various community agencies and groups, including firemen, police, and doctors, to educate them about AT and disability needs in their communities. It was heard several times that persons with disabilities are forcing the non-disabled public to learn about their AT needs by engaging them in discussions. People who use AT were also making the AT visible in order to educate others on what it is, and how it is used, and how it helps those who use it.

For example, one participant noted:

“I also feel that I’m educating the hearing people about how to set up situations so that the hard of hearing can hear better. I’m forcing a lot of discussions, and I want to participate. The only way to participate is to make whole groups cater to me. That’s what I’m doing; I’m making them discuss it.”

In addition to advocating for others and themselves, it was seen numerous times that persons with disabilities established a network of information amongst themselves to educate each other about new devices. Support groups are needed to share ideas. People are always looking further for ways to educate themselves on how their AT needs can be met. They are actively pursuing superior information in order to make more informed decisions about AT that impacts their lives in all facets: employment, health, function, and independent living.

One focus group participant said:

“Our people tell us, we tell each other.”

The focus group participants strongly felt that more advocacy on a system-wide scale were needed. While many of them were self-advocates, and helped others they knew, there was a clear need for persons with disabilities to band together and “spread the word” about AT. They also stated that advocacy groups are providing training to their members and volunteers, but there is no cohesiveness from state to state.

As one self-advocate stated:

“We need to build a coalition of AT users and disability

organizations to educate the public and employers.”

Specific areas for systemic advocacy include those with hidden disabilities needing a bigger voice. Also, it was heard that advocacy was needed so that devices can be found at local electronics stores instead of only being available through special order and at an inflated price.

Strategies to Educate and Inform About AT

Participants in the focus groups wanted to see policy changes enacted that would create a large-scale, public education campaign about disability issues.

Information about AT and disability should be made available in numerous formats, and should be easy to access and locate. Ideas offered included columns in major newspapers devoted exclusively to AT and disability, a national system created so that information provided was consistent and standardized; an AT loan library so people could look at what they were thinking of purchasing and see if it met their needs; a Web site that was easy to find that provided resources for AT vendors, funding forms, and displayed different options of AT for various disabilities.

One area that peaked our interest was the need for a Web site and telephone number that was easy to find and provided vast amounts of good information about AT to California consumers. The Community Research for AT is a project of the California Foundation for Independent Living Centers, which also runs the AT Network, a statewide information and referral service about AT, which in addition to hosting a toll-free 800-telephone number, also has a Web site of AT vendors and service providers accessible via the Internet. The AT network is currently funded by a Tech Act grant to the state. The future of the funding of this project is unknown. In many of our focus groups, people were unaware of the AT Network services. And even more revealing was the fact that many of the participants were unaware of the services that Independent Living Centers provided, even though the majority of the focus groups were moderated by the Independent Living Center staff and in some cases held at the center itself.

While many are aware of the AT Network, and are making efforts to create awareness of the service through various methods: public service announcements on TV and radio, interviews on the radio, booths at trade shows, ads in busses, and other means, it still tells us that there is a lot more work to do before the AT Network becomes a commonplace name that people

will refer to when they need information about AT.

There is a famous phrase used by a major television network, “The more you know,” which we feel encompasses the heart of research and signifies what research is all about. Information is power. The more power and control one has, the more they are able to enact change. With information, people with disabilities are able to make better choices, make informed decisions, decide for themselves, learn and earn.

More information is more power. Having knowledge empowers people to make their own decisions. Not only will CR4AT work with consumers, employers and AT professionals but also we will partner with the AT Network and the ILCs to ensure more consumer information is circulated and made accessible about AT so that this information gap we have identified can be conquered.

AT Action for Change

Action Success Story

Living with Assistive Technology (AT) makes living our lives easier. AT often increases our ability to do things on our own timeline, leaving more time and energy for work, play, friends and family.

AT Action Case Study

Getting the AT we need sometimes depends on “systems” that determine whether we are “eligible” to receive AT through government funding. Medicaid is one of these programs.

In the state of California in 2003, there was a multi-billion dollar budget crisis that threatened cuts to the Medicaid program. Medicaid pays for assistive technology for low-income people with disabilities.

People with disabilities learned about proposed cuts and took *ACTION*. These are the ways they saved AT funding in California.

People with disabilities targeted decision makers—in this case legislators with the significance of AT in their daily lives. In addition, they let decision makers know how much it would cost the state of California if they were forced into nursing homes because of a lack of AT. They got their message across because they wrote, they called, they showed up and spoke up! These activists engaged in the following actions:

- Wrote letters to legislators
- Sent emails to legislators
- Phoned legislators
- Met with legislators in district and capitol offices
- Protested outside legislator district offices
- Rallied at the state Capitol
- Testified at public hearings
- Spoke at town hall meetings
- Wrote “Letters to the Editor” in local newspapers, which were read by legislators
- Interviewed by Radio News

- Guests on Radio programs
- Interviewed by Television News
- Interviewed by Newspapers Reporters

California AT users succeeded in organizing a loose grassroots effort to save AT funding. They worked together with organizations that serve people with disabilities who were able to support the grassroots effort in various ways including providing:

- Meeting space
- Sample letters to legislators
- Talking points
- Media contacts
- Transportation
- Stamps and stationary
- Computer access
- Phone access
- Training and mentorship

California AT users were successful because they would not be ignored. They joined action and advocacy teams at local independent living centers and worked together to save AT funding. They made it clear to decision makers that cutting AT would cost more in dollars and in human spirit—they WON!

As government budgets decrease the funding for assistive technology for people with disabilities is increasingly at risk of being eliminated. AT users can and do successfully come together with organizations and each other in difficult budget times to prevent AT funding from being eliminated. The key is YOU, and the twist is ACTION.

Let's Put it Into Action!

AT Action Items

The Ecological Framework	Strategies
MACRO	Streamline AT process and reduce “red tape”.
	Change funding eligibility requirements to include more devices and reduce medical necessity criteria.
	Provide access to basic medical care, information and education, health-promoting activities and community services to all.
	HMOS and Medi-Cal should provide the same level of medical coverage.
	Pass laws requiring better education of professionals and service providers.
	Mass market AT devices instead of labeling them for specific populations.
	Disability and AT awareness public education campaign.
MESO	Train professionals, employers, service providers and industries who serve people with disabilities on universal design and AT.
	Train professionals, employers, service providers and others on all awareness of disabilities and communication with people with disabilities.
	Involve people with disabilities in the designing of AT devices.
	Increase and improve access to transportation systems.
	Coordinate services and communication between health professionals, services providers, vendors and consumers.
	Provide better and increased advocacy for people with disabilities.
	Approve new AT devices for funding lists as they arrive on the market.
	Repair AT devices in a shorter time frame.

MESO (continued)	Make information available to rural and non-English speaking consumers.
	Make information regarding AT-related tax deductions clearer and more accessible.
	Devices should be compatible with one another and universally designed.
	Devices should be affordable.
	Develop accessibility teams with video cameras to evaluate and explain the importance of accessibility issues.
	Develop AT devices to assist parents with disabilities in caring for their children.
MICRO	Train consumers how to use their AT devices.
	Actively involve consumers in the AT acquisition process.
	Inform consumers about the different AT devices available to them.
	Inform consumers about the AT funding process, how to get the devices they need and from whom.
	Make AT devices portable.
	Make AT devices stylish and fashionable in appearance.

Focus group participants were happy to be asked what work needed to be done to improve their quality of life.

Macro Action Items

Streamline the AT Process:

Many focus group participants felt the funding and acquisition process needed improvement. Forced to navigate through large amounts of “red tape,” some consumers waited large amounts of time to receive services and equipment. People were sometimes shuffled from one professional to another, from one service provider to another, getting assessed, collecting letters and completing documentation procedures. Streamlining this process would trim the months (or years) consumers wait and allow for a more straightforward process.

Change Funding Eligibility Requirements:

Consumers want to see changes made to the eligibility requirements established by the variety of AT funding sources and service providers. In focus group sessions, consumers were unable to take advantage of services because they did not meet service criteria or because the requirements were too stringent. Unreasonable income and property limits created situations where consumers were forced to choose between selling possessions to meet qualifications or trying to pay for devices and services on a less than adequate income. Another requirement was that the device be “medically necessary” and often the equipment could not meet this criteria but was certainly useful and required for daily life.

Provide Access for All:

Focus group participants had varying access to basic needs, which included medical care, information and education, health-promoting activities and community and social services. Providing all consumers with access to these needs would not only increase their quality of life, but also reduce the number of barriers they encounter with regards to services, funding and AT acquisition.

HMOS and Medi-Cal Should Provide the Same Level of Coverage:

Although there is a maze of medical insurance in California, the focus group participants often repeated that it was unfair how different the coverage was for people served by Medi-Cal and those with Health Maintenance Organization (or PPO) coverage. Suggestions were made to even out the benefits and ensure devices and technology were covered under any new agreement.

Pass Laws Requiring Better Education of Professionals and Service Providers:

Consumers would like to see the government take the initiative in ensuring professionals and service providers are properly trained about disability and AT. Creating laws to address the lack of professional education will help to establish a higher standard level of education for all those who serve people with disabilities.

Mass Market AT Devices:

There is a two-fold benefit to move towards a mass marketing strategy for more AT devices. If AT devices were mass marketed and available in retail stores, they would be cheaper due to the higher demand. As long as devices can be labeled as “special,” the prices can remain high. Changing the marketing strategy would also make devices readily available to consumers because more AT would be available in local communities. More AT devices might not only be available at specialty stores, such as Radio Shack, but at mass merchandisers as well.

Disability and AT Awareness Public Education Campaign:

One of the biggest action areas cited by consumers was a need for a disability and AT awareness public education campaign. It was very common to hear about encounters focus group participants had with insensitive bus drivers, store managers and the general public. Providing information regarding disability to the general public would allow consumers to have a more pleasant experience out in the public. It could also affect public sentiment, and affect the tone of public policy.

Meso Action Items

Train Professionals, Employers, Service Providers and Industries on Universal Design and AT:

Members of the above mentioned groups do not have an equal knowledge base about AT and universal design. Sometimes when people with disabilities seek professional assistance, the professionals are not the “experts” they appear to be. When service providers do not have all of the information available to them, then is no guarantee the consumer will have all of their needs met. Educating professionals, employers, service providers and disability-serving industries will provide improved information and service delivery to the disability population.

Train Professionals, Employers, Service Providers on Disabilities:

Consumers expressed a desire to professionals and service providers better educated. This included education about members of the disability population. Professionals also need training concerning multicultural issues and disability

so they may better serve the disability community. Currently, most cultural diversity training programs do not address disability.

Involve People with Disabilities in the Designing of AT Devices:

People with disabilities need to be involved in the designing phase of AT devices. People with disabilities are the consumers who use these products and services on a daily basis, so it is important their feedback is included. The life experiences of people with disabilities make them experts in the regular use of AT devices and services, thus it follows their input is necessary in making devices and services more effective.

Increase and Improve Access to Transportation Systems:

Many people with disabilities use public transportation systems to get around. Unfortunately these transportation systems are not always adequate, especially in rural areas. Drivers and service personnel are not personable, buses and shuttles do not run on reasonable schedules, and others do not show up at all. Efficient and accessible transportation systems are an important component of independent living and community integration for consumers. Improvements to current systems must be made and further systems established so consumers may commute to work, run errands, shop and do whatever else they need to do.

Furthermore, these systems need to be accessible to seniors and people with disabilities. If there are seats reserved for these populations, both drivers and passengers need to honor the reservation. Vehicles need to be fully accessible and drivers must be trained so they can provide appropriate services.

Coordinate Services and Communication:

Consumers would enjoy better benefits if services and communication could be coordinated. Focus group participants shared stories of disjointed services, where professionals provided conflicting information and practices. This delayed the acquisition of equipment and receipt of services for many participants. Professionals and service providers need to communicate with each other to best meet the needs of their consumers. With open lines of communication, service delivery can be improved and consumers can enjoy the benefits of equipment and service to best suit their needs.

Provide Better and Increased Advocacy:

Focus group participants expressed an interest in having someone available to help them through the endless red tape of the AT process: an advocate. This person could serve as a personal point-of-contact for AT services, an information source for AT and related services.

Having community advocates widely available would also be beneficial to people with disabilities from diverse cultural backgrounds. In an effort to increase equal access to information and services, ethnic minority community members are interested in using community representatives as a means to educate others about AT. Using a “go-between” could help community members to be more receptive to new information because it could be delivered in a manner that would be respectful to the population.

Approve New AT Devices:

Updated and more innovative AT equipment is being developed all the time. Unfortunately, consumers find the funders’ lists are not keeping up with the wealth of technology available. How can consumers be assured they are being provided with the best technology available if the approved equipment list is not up-to-date? Service providers and insurance companies need to make sure they are knowledgeable about the different AT devices and services available so they can be available and fundable to people with disabilities.

Repair AT Devices in a Shorter Time Frame:

When consumers send in their equipment for repairs, it is important for it to be returned in a timely manner. A common complaint from focus group participants was a long waiting period for repairs on their AT. Quality of life is affected when a person with a disability is forced to cope without the device that person to use the telephone, go grocery shopping, carry their child or whatever the AT helps them to do. Keeping repair times at a reasonable length would help to ease the stress a consumer must deal with. If repairs require an unusually long length of time, loaner equipment should be made available to lessen the consumer’s inconvenience.

Make Information Available to Rural and Non-English Speaking Consumers:

All consumers are not receiving the same level of information about assistive

technology. Rural people with disabilities often do not have access to the same services as their urban and suburban counterparts. People who speak little or no English also have problems accessing information and services because information is not available in their native language and service providers do not speak their language. In both cases, consumers lose. Information that is critical to an improved quality of life is withheld. Access to disability and AT services needs to be made widely available so all consumers may benefit from the services and devices available. This includes multilingual information and services along with outreach to rural and outlying areas.

Make Information regarding AT Tax Deductions Clear and Accessible:

Currently information regarding AT-related tax deductions is complicated and not widely distributed. Many people and organizations are unaware they might qualify for tax deductions because of assistive technology they may have purchased. People need to know what information and resources are available to them. Information about tax deductions should be clear, accessible and available so more people would be able to take advantage of a benefit that has been established to help them. (See Assistive Technology and Taxes: Not a Perfect Fit <http://www.atnet.org/news/2003/apr03/040101.htm>)

Devices Should be Compatible and Universally Designed:

Some participants who used multiple AT had problems when trying to coordinate their use, this was especially a problem with computer hardware and software. Consumers want AT to be compatible with other devices it might be used with. For example, with computers, consumers want adaptive computer programs to be compatible with both the operating software on the computer along with any other adaptive hardware or software the consumer may use. Designing AT so it may be easily used in conjunction with other AT increases the ease of use. This allows consumers to enjoy the benefits of their equipment without all the frustrations incompatible equipment.

Devices Should be Affordable:

Many of our focus group participants self-purchased smaller and inexpensive devices from local retailers, such as Radio Shack. Unfortunately, the number of devices in this price range is very limited. AT should be more affordable so providers in funding streams are not gouged by the high prices of equipment. If prices were lower, people with disabilities might not have to deal with such

stringent and unreasonable requirements set by funders. Making AT more affordable also benefits the consumer, because people would be able to pay for more AT out of pocket.

Develop Accessibility Teams to Evaluate Accessibility and Educate Others:

Consumers want society to understand not only what accessibility looks like, but what it means to members of the disability community. Focus group participants propose creating accessibility teams that would do assessments with video cameras not for the purpose of lawsuits, but to educate others. The teams would be an opportunity to provide an individual-based education campaign to increase the level of accessibility in public places for consumers.

Develop AT Devices to Assist Parents with Disabilities:

Many of the definitions and criteria used to define a consumer's "need" do not include parental functions. The needs of this sub-population often are not thought of in the realm of people with disabilities. Those who design AT devices should remember that people with disabilities have the same needs, wants and responsibilities as members of the non-disabled population, and all of those needs, wants and responsibilities may potentially need accommodations. Devices must be designed to help parents with disabilities care for and attend to their children, both with and without disabilities. This will help make parenting duties easier for people with disabilities caring for children. As these devices become more and more available, it is also imperative that funding streams integrate this different type of functional need into their eligibility criteria for funding programs.

Micro Action Items

Train Consumers How to Use AT Devices:

Consumers must receive complete and proper training on their AT devices and services when they first receive them. Training on the equipment includes not only how to use the AT, but how to recharge it or replace batteries (if needed) and the procedure to get it repaired. Consumers are less likely to reap all the benefits of their devices if they do not know how to use them. Without training, there could be a potential for abandonment or injury.

Actively Involve Consumers in the AT Acquisition Process:

The majority of focus group respondents were not active participants in obtaining their AT. Someone else decided what device they would receive and all of the consumer's preferences might not have been taken into account. It would be helpful to consumers if they could provide some input on what qualities might important to them in AT equipment or service. For example, if a consumer has limited space in their living quarters, it would be important for to obtain a wheelchair that could navigate in that space. A service provider would need to take this information into account so that the best available AT was provided to the consumer. A consumer might be more likely to use the equipment if he or she had a hand in the decision-making process.

Inform Consumers About AT Devices:

Consumers must be made aware of what AT is available to them. Professionals and service providers need to share their knowledge about the wealth of technology that is available to help consumers live, work and play. With information about what AT is available, consumers can feel empowered and can make better choices concerning the best equipment for them.

Inform Consumers About AT Funding Process:

In focus groups, some participants informed us they didn't have equipment because they did not know there were organizations and agencies that would purchase it for them. Consumers need to be informed about which agencies and organizations are available to help them acquire AT.

Make AT Devices Portable:

People with disabilities need more of their AT devices to be portable. Items such as TTYs, scooters and electric wheelchairs were devices commonly used by consumers, but their portability was limited. For example, although there are portable TTYs available, the batteries these devices use are expensive and drain very quickly. With scooters and electric wheelchairs, many consumers are not able to ride in cars because their equipment will not fit or is too heavy. Consumers do not want to be so limited in their options because of their AT equipment. Devices should be made so consumers have a variety of choices available to them. Accommodating a disability is supposed to open doors for the consumer, not shut them.

Make AT Devices Stylish and Fashionable:

For some seniors and people with disabilities, it is important that AT does not look “institutional.” Devices should be stylish and fashionable. AT should be available in a manner that allows a person to continue to express their individuality through characteristics such as color and size. Furthermore, these more stylish and fashionable devices should not be seen as an extravagance and should be equally covered by funders.

Research for the Coming Years

Recommendations for Future Research Topics

1. High Tech—Low Tech: Benefits and Costs

Two categories of technology need to be specifically researched to understand the relative impact on independent living. The first type is low tech and the second is high tech. Computers—both large and small—are important tools for independent living but they are also expensive and often cannot be easily fixed by users. Low tech devices such as nonslip mats in bath tubs or devices to open jars can be very helpful yet very low cost. Research needs to look at the costs/benefit of both high tech and low tech. Some people need computerized technology to enable them to communicate or move a wheelchair. The people who are dependent on these higher tech, higher cost devices may end up stuck if the equipment breaks or if funders are unwilling to support these options. Research on the advantages (and disadvantages) of both high and low tech devices will help inform funders and vendors as well as consumers.

2. In Home—Out of Home: Independence and Community Participation

Although many people use equipment and technology of many types within their homes, we also need to use technology to be part of the world outside our homes. Disabled people need to have access to the local stores, houses of friends, religious institutions and community centers. To access these places there are door-opening devices and transportation or mobility aids, including access to buses and taxis. Many places in the United States, and specifically California, need more services that allow people to leave their homes and be part of the community. Elevators or lifts in some places provide help for people with physical disabilities, but we still need to understand more about how to support people with cognitive and mental disabilities.

Adults who previously lived with parents or family, or people who were once in nursing homes or group homes, may now be living on their own or with a partner. Technical aids to assist people in their homes with cooking, cleaning, using the phone and being alerted in emergencies need to be assessed for how successful they are. Research needs to look at how effective equipment is in homes and in getting people to be part of their communities.

3. Mental Health and Technology

In our research we identified the benefits of communication and computer technology for people with mental health disabilities. We know there is a lot of research needed to help people with mental health disabilities be more supported using technology. Most of the technology looks at people with sensory, physical and cognitive disabilities but not mental health disabilities. One example of research on people with Alzheimer's Disease is the use of personal digital assistants (PDAs) to provide records and reminders of activities. This is just one example of how a mainstream device can be used to accommodate a disability, in this case a memory difficulty. We need to do more research on how equipment can be used to support people with mental health disabilities—not just in the health sense of helping them with a diagnosed disability, but in being part of society, going to work, having families, and participating in recreation.

4. Health, Rehabilitation and Living Well

Research needs to take into account that health is not simply the absence of illness, and rehabilitation is not only when one first becomes disabled. Technology such as braces, crutches, splints, and hearing aids can all be part of getting back into a higher functioning state. Health care providers must recognize the connection between rehabilitation services and overall health as well as living well.

Research needs to look at how services and equipment are used after extended periods of disability, and when disability status changes. For example, people with arthritis, Multiple Sclerosis, or even hearing loss may require new equipment every year. Degenerative disabilities as well as disabilities that interact (blindness and diabetes, for example) may require alternative forms of technology, either adjustable or replaceable. Research needs to be conducted on the connections between rehabilitation and living well and how the medical system treats people with technology needs.

5. Employer Attitudes, Accommodation, and Real Jobs

People with disabilities have identified the unwillingness of employers to provide equipment as a major barrier to working. In addition there is an ongoing problem related to Department of Rehabilitation funding of devices for employment purposes. Our research has pointed out that we need to know

more about the beliefs and understanding of employers towards disabled people. We do not really understand why they are so reluctant to provide equipment and hire disabled people. We already know that the idea that insurance will be costly or even that accommodations will be costly is unsubstantiated. We also know that there are still some ideas that people will miss work or take a lot of sick leave if they have disabilities. Research is needed to understand the connection between provision of technology and hiring of people with disabilities. We believe that disabled people will not be successfully employed if they are not provided with suitable tools for working.

One additional research area is the connection between unions and the employer in terms of what benefits and technology will be provided to all staff—with or without disabilities—and how this might impact the hiring of disabled people.

6. The Internet: Indispensable

Many people with disabilities are dependent on the Internet for communication, work, education, and personal needs. Deaf people are now using two-way pagers and instant messaging for communicating with both Deaf and hearing people, instead of the phone. Disabled people often use the computer for ordering clothes and food to be delivered, and others use the Internet to communicate easily with support staff and service providers. Research has been done on accessibility issues for people who are blind, as well as web site design access in general. We still need to know more about the relationship between using the Internet and accessibility to the community as well as health and work opportunities.

7. People Without Technology—Marginalized Populations

Although technology seems to do a great job of empowering people with disabilities, being without it has a very negative effect. People who cannot afford devices or people who do not have insurance might have to live without a very basic service such as a cell phone or power wheelchair. Depending on the type of equipment, the costs, and the relationship to “medical necessity,” poor people are often unable to access technology. Some of the poor people are also people who speak another language, like Vietnamese or Spanish. For some of these people the technology might not be appropriate if it is not provided in alternative languages. Even people who do speak English but are a racial or ethnic minority might be marginalized from the most important

equipment due to racism and poverty. Research is needed to identify the reasons that people do NOT have technology and how the issues of poverty and race and language intersect. This is not an easy issue to research as the population tends to not participate in research activities. However, it is the lack of research that provides an excuse to do little to make change possible.

8. The More You Know: Knowledge is Power

All of our research pointed to the importance of knowledge. Knowing your rights, knowing the equipment options, and understanding the way the system works all lead to better success in meeting technology needs. But knowing the right information is not easy if you do not have access to reading, English, the Internet or the phone. Most consumers were able to learn a great deal by reading or talking to someone. We need to research how people can get access to information if they cannot speak English or cannot read. One potential suggestion is the computer equipment that reads the contents of the screen out loud, a screen reader. This will allow someone without good literacy to still search the Internet and find information about equipment and programs that might be helpful. However, the irony is that in order to get access one needs to already have a computer, a screen reader, and other related devices. Research is needed to identify how best to get access for people who do not have computers or do not have literacy to read English.

9. Managed Care, MediCal, Medicare

Research is essential to understand the funding rules, requirements, and processes for various forms of insurance, including private and public options. Many people with disabilities do not have access to private insurance but they are restricted to very few pieces of equipment if they are on MediCal or Medicare. Even the minority of people with access to private insurance, using health maintenance organizations or preferred provider organizations still face rules and restrictions in terms of what technology will be paid for under durable medical equipment. Research is needed to give consumers more information about the specifics of a range of health service providers and also to do some assessment or comparison between the options. Action items are also needed to make extensive changes in how services are funded.

Conclusion

Focus groups provide a value in research that cannot be found with surveys and collecting quantitative data. Focus groups allow us to see trends that occur, as well as quality issues that have not yet been addressed. From the results of our focus groups, we can witness the many benefits AT has had in our participants' ability to function on both an independent level as well as an integrated part of their communities. Individuals were better enabled to work, parent, interact in the community, remain healthy and pain-free, be safe, and live independently with their AT.

Consumers in the CR4AT focus groups spoke to the quality of life—health, energy, and participation—that AT has provided for them. We think you can say the same about “AT” for non-disabled persons: microwaves, washers/dryers, cell phones, navigational systems (for those of us who are chronically lost), personal digital assistant (PDAs) all help “non-disabled” as well as disabled. All of us are better able to function as a result of these helper technologies. One conclusion is that we need to stop looking at assistive technology as special and people who need it as special. Just like a microwave or a dishwasher is now pretty standard for most people (not all but they are cheap enough to be in reach of many people), hearing aids, wheelchairs and Braille-n-Speak should become standard for people with disabilities.

One trend that surfaced from the focus group results suggested that the more disabling an individual's condition, the more technologically advanced the AT they required. Researchers observed that current AT systems are more effective in providing for those with severe disabilities than those with marginal or recently acquired disabilities. Less severely or recently disabled individuals were less aware of AT available to them, and less likely to be receiving the AT that they would find beneficial. CR4AT would like to further investigate this phenomenon, and research ways to assist all persons with disabilities in receiving AT.

It is already well known that funding AT devices can be an arduous and time-consuming process. A consumer must know the “ins and outs” of a funding agency's requirements before getting the device approved, and then delivered for use. Because every agency who funds AT has its own set of eligibility requirements, including a list of devices that will and will not be funded, and an ingrained system that seems to work against the consumer, many people give

up completely and exist with substandard devices, or none at all. The agencies that fund AT have “maintained eligibility criteria that are based upon the medical model definition of disability [in which] medical professionals must certify that an applicant has a disability. The eligibility criteria ignore the fact that environmental barriers frequently limit the full and equal participation of people with disabilities in employment and their community” (Council of Canadians with Disabilities, 2000). The deep-seeded medical model embedded in these agencies does not consider that persons with disabilities must leave their homes to participate actively in work and in their communities. “It does not engage in positive and meaningful ways with those who have disabilities, so that they are not socially ostracized and so become a barrier to their social participation” (Duchan, 2001).

There is a nearly universal experience of frustration encountered when dealing with third party payers for AT. The difficulty of third party payers funding AT needs highlighting. A call to action needs to be formed to change the definition of assistive technology to encompass more items that impact a person’s ability to live independently. A consumer model needs to be adopted in all funding agencies. Specific solutions to this problem include: a national system/standardization of AT; changing the definition of AT to encompass a more holistic approach to living with a disability; places that allow a person to try AT before it is purchased, thereby reducing the waste of millions of dollars on inappropriate AT; streamlining the funding process through the funding agencies by making the forms more accessible, keeping information on file; and lastly AT service providers and vendors accepting and accruing accountability for their services.

As part of funding, there also needs to be opportunity to “try before you buy” to make sure such equipment is appropriate. Most of the time, consumers buy equipment, and it doesn’t fit the consumer’s needs. Because people didn’t shop well enough, look well enough, or were not able to try it out, they end up getting less than the optimal device. If they can try out the device first you can ensure it is functional and matches with the individual (Dr. M. Clark, personal communication, July 11, 2003).

Over and over again, the focus groups have revealed to us that changes in the system need to be made to make AT easier to obtain. It has also been stated there is a need to eliminate the bureaucratic problems inherent in the AT system. Solutions to this vast problem would include creating AT that is more mainstreamed, which in turn creates a larger market for AT devices, increasing

demand, which in turn lowers the pricing and creates a more level market.

“Make it easier to obtain AT items; eliminate the problems inherent in the programs as they exist today.”

Another solution would be to add to the list of devices that are covered by funding agencies—create a more holistic approach to AT. Include devices that are not only functional, but also increase independent living and community integration outcomes. For example, if a wheelchair is provided to someone, also provide a ramp to get in and out of the home.

Streamlining the process to obtain AT is another issue that was revealed in all focus groups. By making the information more available on what agencies exist to aid people with disabilities, much of the frustration, confusion, and anger can be alleviated. It was suggested that agencies collaborate with one another, tell consumers about their options, and make forms available in public places, on their websites, and in alternative languages.

We see individuals who are able to wade through the system, but there are so many others who have given up or take devices that do not meet their needs, because they do not have the stamina or wherewithal to continually fight for what should be considered necessities instead of luxuries. Overall, the barriers to AT are insurmountable and we will continue to see more and more people not participating to their fullest extent in communities and their own lives. Unless change happens on a systemic level and filters down to those who serve individuals with disabilities and then people with disabilities who are being served, these barriers will continue to proliferate.

Our participants themselves had clear opinions on areas that needed improvement, and some ideas for action. Many stated the need for more education and information regarding available AT and means of funding it. Some called for the implementation of try-out centers, where consumers could test out equipment before committing to it. Others requested a way of ensuring the accountability of vendors, who were sometimes seen as insensitive or irresponsible to the needs of those they served.

Helping to increase societal awareness and eliminate stigma regarding the users of AT may encourage those whose lives could benefit from assistive technology to pursue it. Those respondents who had abandoned their AT, not wanting to be visibly associated with the disabled communities who depend on

such devices as wheelchairs or hearing aids, typify the public mentality regarding disabled persons as a separate category of individuals. When persons realize that they have nothing to lose and only stand to gain by trying AT, they may find that they will never regret the change in their life.

By being inclusive instead of exclusive, and sharing information, people with disabilities are able to gain the knowledge they need to make informed decisions about their welfare. One of the major goals of this research project is to be able to share our results with consumers to better enable them to make informed decisions and choices about AT. In addition, we hope to empower them to better be able to navigate through the various services agencies that must be dealt with to obtain AT.

“If the agencies and the specialists who share information and have the resources about AT and if the information is passed on to disabled community. Then every stakeholder could share in the knowledge and more would benefit.”

Evident throughout the course of this paper is the fact that many of these findings are *already known* within the disability community, and they have been known for a very long time. So, the next question in the research cycle becomes, “Why has nothing changed if we know what the problems are and have solutions to these identified barriers for persons with disabilities?”

Based on the results of the CR4AT focus groups, the project’s next step is to gather quantitative or statistical data from over 3000 Californians with disabilities. Armed with this much information on the current status for persons with disabilities, our goal is to inform as many people as necessary, including the legislators, the manufacturers, the funding agencies, and anyone whose ear we can grab, to *really listen* to the results and engage in a full-fledged attack. We hope to begin by revising the terminology “medical necessity.” As has been revealed, that term is rigid in what people are allowed that enable them to move toward increased independence. Additionally, as stated previously, we would like to see the types of devices funded by agencies expanded. To our knowledge, those lists have not been updated for many years. If what one needs is not on the list of approved devices, then appeals must be made continuously. To increase the participation of people with disabilities in their communities and keep them out of institutions, AT needs to be put into the hands of the consumers who need it.

One participant summed it up very succinctly for us:

“There needs to be collaborative purchasing of AT, and a push on trying to increase priority that the professionals place on AT. Also building more knowledgeable consumers in terms of consumers and families, because if they ask for it, the providers will be forced to look into it. Both the supply and demand needs to be increased. In a corollary to that, I won’t say we need more specialized pots of money, but getting the AT into the mainstream of services and support provided to people with AT—AT is considered specialized stuff and it should be a core part of service.”

We can also recognize that some elements must change before every individual can embrace the opportunity to function at an equal level. In our continuing goal to enable all persons with disabilities to pursue the independent lifestyle to which they have a right, the CR4AT project on behalf of the CFILC will apply what we have learned to engage in more informed and effective advocacy that directly reflects the needs of the community we represent.

Is all this worth it? Does AT really improve lives? In the words of one participant:

“Immensely. And you don’t know that until you actually have it then you think, ‘WOW, what a difference. I can hear, I can function now’.”

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Product and Services List

ABLEDATA (<http://www.abledata.com>)
Access Services (<http://www.asila.org>)
AT Network (www.atnet.org)
Braille 'n Speaks (www.freedomscientific.com)
Braille Institute (www.brailleinstitute.org)
California Children's Services (<http://www.dhs.cahw.net.gov/pcf/cms/ccs/>)
California Department of Rehabilitation (DOR) (www.rehab.cahw.net.gov)
California Public Utilities Commission (CPUC) (www.cpuc.ca.gov)
California Foundation of Independent Living Centers (CFILC)
(www.cfilc.org)
Continuation of Health Coverage (COBRA)
(www.dol.gov/dol/topic/health-plans/cobra.htm)
Community Research for Assistive Technology (CR4AT)
(<http://www.atnet.org/CR4AT/home.html>)
Deaf and Disabled Telecommunications Program (DDTP) (www.ddtp.org)
Easter Seals (www.easter-seals.org)
Fry's Electronics (www.frys.com)
Kaiser Permanente (www.kaiserpermanente.org)
Medi-Cal (www.medi-cal.ca.gov)
Medicare (www.medicare.gov)
National Resource Center for Parents with Disabilities (NRC)
(<http://www.abledata.com/text2/parentin.htm>)
Paratransit Services
(www.paratransit.net)
Quadjoy Mouse (<http://quadjoy.com/>)
Radio Shack (www.radioshack.com)
Sandy Welner Table (<http://www.disabledparents.net/examtable.html>)
Social Security (www.ssa.gov)
Through the Looking Glass (TLG) (<http://www.lookingglass.org/>)
UPS (www.ups.com)
Veterans Benefits Administration (www.vba.va.gov)
Windows Software (www.microsoft.com)

How it Works – Feedback Form

Thank you for reading the CR4AT publication, “How it Works – AT Narratives from California.” Your answers to the following questions will help us refine our community research efforts.

The California Foundation for Independent Living Centers, a non-profit disability advocacy group in coordination with CSU, Northridge – Center on Disabilities is conducting research on technology used to facilitate outcomes for people with disabilities. The phrase “assistive technology” refers to any device that a person with a disability uses to live or work more independently. It can be a modified workstation, a walker, or even Velcro on a pen. This project is funded by a grant from the National Institute on Disability and Rehabilitation Research.

1) Demographic Information

- A. Gender Male Female
- B. Age Under 18 18-25 26-35
- C. I am from a/an Rural Urban Suburban area
- D. Ethnicity
- African American Asian American/Pacific Islander
- Caucasian Hispanic/Latino
- Mixed Race American Indian
- Other Decline to state
- E. I am a (check all that apply)
- Person with a disability
- Parent of a person with a disability
- Employer
- Educator

- Vendor/Service Provider
- Researcher
- Other _____

F. Primary disability

- Mobility
- Sensory
- Learning
- Psychiatric
- Other
- None

2) Does this book cover issues of importance to you?

- They are all important to me
- Some are important to me
- Not very many are important to me
- None are important to me

3) What are we missing?

4) What issues are urgent now?

5) Out of the urgent issues, which ones should be addressed now?

6) What kind of research would you participate in if you wanted to assist with the project?

	Yes	No	Maybe
Surveys	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal Interviews	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Focus Groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical Studies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7) Please provide an experience (either positive or negative) that you have had regarding assistive technology.

Please return survey to

Community Research for Assistive Technology Project
Myisha Reed, Research Project Coordinator
660 J Street, Suite 270
Sacramento, CA 95814

(Voice) 916-325-1690
(TDD) 916-325-1695
(Fax) 916-325-1699
(Email) myisha@cfilc.org

Thank you!

Do you want to know how you can participate more actively in this project?
Please contact Myisha Reed, Research Project Coordinator,
at (916) 325-1690 or send mail to:
660 J Street, Suite 270, Sacramento, CA 95814.

HOW TO CONTACT THE COMMUNITY RESEARCH FOR ASSISTIVE TECHNOLOGY PROJECT

Call us

1-916-325-1690 (Voice)

1-916-325-1695 (TDD)

For Information and Referral regarding
Assistive Technology in California, please contact
the Assistive Technology Network at

1-800-390-2699

Fax Us

1-916-325-1699

Explore the AT Network

<http://www.atnet.org>

Explore the California Foundation for
Independent Living Centers

<http://www.cfilc.org>

Write Us

California Foundation for Independent Living Centers
Community Research for Assistive Technology Project

660 J Street, Suite 270
Sacramento, California 95814

**Community Research
for Assistive Technology**



Improving Access Through Collaboration

