

# **Tools for Living**

## **Assistive Technology Experiences of Californians with Disabilities**

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California Foundation for Independent Living Centers

A publication of the  
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**Community Research  
for Assistive Technology**   
*Improving Access Through Collaboration*

# **TOOLS FOR LIVING** *Assistive Technology Experiences of Californians with Disabilities* **Yeager • Kaye • Reed**

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All the respondents -consumers from the California Independent Living Centers- who took the time to fill out our survey. Without you, this information would not exist.

# In Memory of Tanis Doe, Ph.D. – our first Principal Investigator

In 2000, the National Institute on Disability and Rehabilitation Research put out a call for projects that incorporated members of the disability community to conduct research on the effectiveness of assistive technology from the viewpoint of people who use AT. The members of the California Foundation for Independent Living Centers, a state association for Independent Living Centers, and its staff could not see itself doing this. After all, research is for those “clipboard people” at the University. But when we began to be open to the thought of doing this work, the right person came along to lead us to it. And lead she did!

Non-traditional in her approach to learning, Dr. Tanis Doe was a master teacher who personally understood oppression, disability, women’s and minority cultures and she knew how to conduct participatory action research. This is the type of research that is tailor-made for the disability community. We are the experts about what affects us, so we should be guiding and interpreting the research. Tanis opened the door for all of us to participate and see that we were indeed, the experts!

Watching her teach ILC directors and staff about classifying data, using vegetables as a metaphor, was to watch a gifted teacher. All of us were instantly captivated. Tanis took ILC staff with a variety of disabilities and taught them how to conduct focus groups, code responses and look for patterns. She helped the staff and other members of the research team to write the first two books



and developed the first quantitative survey and began to analyze the first results. Always, she incorporated consumer feedback and ideas into the work of this project. She instilled the idea that we could do this work without degrees in research. As a result, many of the California ILCs are quite comfortable to participate in community-based research projects with other collaborators in their local communities.

At the end of year three of this project, in August 2004, Tanis unexpectedly died in her home in Victoria, British Columbia. Everyone who worked closely with her on this project was devastated. How could we continue? Through guidance and careful prodding by our NIDRR project officer, Dawn Carlson, PhD, the encouragement of Ken Galeai, PhD and



others, we picked ourselves back up and started again.

We found Steve Kaye, PhD at the University of California, San Francisco, whose ability to work with and respect our community is well documented in his work, having written the publications *Disability Watch, Volume 1* and *2*. Steve became the Co-Principal Investigator and the work you see in this book, is a tribute to his ability to honor Tanis' foundation and help us bring the data to light. A true collaborator, we have all come to appreciate one another's skills and perspectives.

The three major staff who have been involved in this now 6-year project have all gone on to learn more about research. Amy Noakes, the first project director is finishing her Masters in Public Policy at the California State University, Sacramento. Myisha Reed, the second project director is pursuing her Masters in Public Health at the University of Washington. Patricia Yeager, the current Principal Investigator has left the position as director of CFILC to pursue her PhD in Rehabilitation at the University of Northern Colorado. All of us have learned that community-based research gives us good data to inform our advocacy. We sincerely hope you will take this data and use it in your advocacy to improve access to assistive technology-tools for living- for people with disabilities in California and in the U.S.

Tanis would be pleased.

A handwritten signature in black ink that reads "Patricia Yeager". The signature is written in a cursive, flowing style.

Patricia Yeager  
Principal Investigator

# Foreword

by Laurence Paradis<sup>1</sup>

These are exciting times for people with disabilities due to developments in assistive technology (“AT”). For most of human history, disability often meant a life-sentence of exclusion from mainstream social and economic life. Recent developments in AT, however, now offer people with all kinds of disabilities new opportunities for integration, independence and full participation in mainstream life that were not even dreamed of a generation ago. Such AT continues to evolve at an ever faster rate, with new devices coming onto the market every year that increase mobility, minimize communication barriers, and make possible what seemed impossible not long ago.

My own personal experience mirrors the opportunities available through AT. When I first became disabled during law school and could no longer stand or walk, I knew almost nothing about AT. My first mobility aid was a 55 pound clunker of a manual chair that worked fine in the hospital, but was almost impossible to use independently to get around outside in the community. I literally had to wait for strangers to pass by to ask for help in pushing this chair up even the smallest slopes on campus. The idea of going out to a store or library without help was out of the question. This dependency and isolation was just as hard to deal with as the underlying physical impairment. The future seemed bleak.

25 years later, the world is a different place. With AT such as a power wheelchair and an

adapted van with hand controls, I am more integrated, independent and functional than I could have imagined. Many opportunities, including employment, parenting, outdoor recreation, and other mainstream activities, have become part of my daily life.

Yet such AT is not equally available to many in our society. All too often, people with a wide range of disabilities find they are still denied access to fundamental mainstream activities due to a lack of assistive technologies. Often, they don’t even know about the assistive technology that could mitigate their impairment. Other times, they know what is needed, but are without financial and other resources needed to obtain essential AT. This gulf between the opportunities offered by AT, and the actual extent to which AT is provided, is even larger for many in minority ethnic communities and for those who are unemployed.

This publication provides invaluable insights into all of these issues. Using modern survey tools, the authors have investigated the role which AT plays in the day to day life of people with various kinds of disabilities and in various population groups, as well as the barriers that prevent people from obtaining needed AT. The authors also present specific action plans for fixing these barriers. Advocates for people with disabilities, as well as researchers and policy makers, will find this report a crucial resource on the role of AT in today’s American society.

---

<sup>1</sup> Mr. Paradis is Executive Director of Disability Rights Advocates, a national nonprofit legal center based in Berkeley, CA.

# Executive Summary

Community Research for Assistive Technology (CR4AT) was a five-year research project conducted by the California Foundation for Independent Living Centers and funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education. The purpose was to understand the need for and usage of assistive technology (AT), along with its benefits and drawbacks, among Californians with disabilities. Unlike traditional research projects, in which the population under study are relegated to the role of research subjects, CR4AT included people with disabilities in all phases of the research, including project leadership, work-

ing alongside professional researchers. In mid-2005, during the final phase of the research, a random sample of consumers of Independent Living Centers throughout California was invited to complete a survey about their AT usage. Nearly 2,000 consumers responded, and the results demonstrate the crucial importance of AT to this population. Also apparent are disparities in usage by age, race, ethnicity, and education, high levels of unmet need for AT, and financial and informational barriers to obtaining needed devices. Key findings from the survey are summarized below.

<b>Key Findings</b>	<b>Page</b>
<hr/> <b>Characteristics of the Respondents</b> <hr/>	
<ul style="list-style-type: none"><li>A majority (55 percent) of the consumers of Independent Living Centers throughout California who responded to the survey had multiple disabilities. The most common disability types were mobility (63 percent), mental health (29 percent), cognitive (24 percent), and visual (23 percent).</li></ul>	20
<ul style="list-style-type: none"><li>More than three-quarters of respondents (76 percent) had annual household incomes of less than \$20,000; 44 percent had less than \$10,000 household income per year.</li></ul>	24
<hr/> <b>Assistive Technology Usage and Disparities</b> <hr/>	
<ul style="list-style-type: none"><li>About two-thirds of respondents (66 percent) used some form of AT in their daily lives; nearly half (49 percent) used multiple devices.</li></ul>	29
<ul style="list-style-type: none"><li>People with mobility impairments were the most likely to use AT (83 percent), followed by those with hearing or visual impairments (80 and 77 percent, respectively).</li></ul>	30
<ul style="list-style-type: none"><li>Of respondents with a single type of disability, only 13 percent of those with mental health disabilities used any kind of AT, as did only 22 percent of people with cognitive disabilities.</li></ul>	31

<b>Key Findings</b>	<b>Page</b>
<ul style="list-style-type: none"> <li>Usage of AT increases with age among ILC consumers, doubling from 47 percent of 18- to 24-year-olds to 95 percent among those 85 or older.</li> </ul>	33
<ul style="list-style-type: none"> <li>The oldest respondents were three times as likely to use low-tech AT devices as the youngest respondents, but only half as likely as the youngest respondents to use high-tech AT devices.</li> </ul>	34
<ul style="list-style-type: none"> <li>Usage of assistive technology is much lower among underserved racial and ethnic minority groups. For example, only 57 percent of African Americans and 59 percent of Latinos reported using any type of AT, compared to 71 percent of whites.</li> </ul>	38
<ul style="list-style-type: none"> <li>Usage of AT increases dramatically with educational attainment. A majority (53 percent) of respondents with graduate degrees were heavy AT users, reporting 3 or more devices, compared to less than a quarter (23 percent) of those without a high school diploma.</li> </ul>	41
<ul style="list-style-type: none"> <li>Usage of more costly AT devices varies substantially with income. For example, among respondents with mobility impairments, 18 percent of those with less than \$35,000 annual household income use power wheelchairs, compared to 29 percent of those with higher incomes.</li> </ul>	45
<b>Barriers and Unmet Needs</b>	
<ul style="list-style-type: none"> <li>Nearly half of respondents expressed unmet need for assistive technology, with 45 percent reporting that there were devices they needed but did not have.</li> </ul>	50
<ul style="list-style-type: none"> <li>Two-thirds (67 percent) of blind respondents reported unmet need, as did 60 percent of those unable to walk and 57 percent of those who were hard of hearing.</li> </ul>	50
<ul style="list-style-type: none"> <li>The main reasons for unmet need were financial, with 61 percent of those with unmet need reporting that AT was too expensive and 53 percent that it was not covered by their insurance or public healthcare program.</li> </ul>	53
<ul style="list-style-type: none"> <li>Unmet need is greatest for more costly equipment like power wheelchairs, scooters, computer hardware or software, adapted or ordinary vehicles, and hearing aids.</li> </ul>	54
<ul style="list-style-type: none"> <li>Consumers and their families are the #1 source of payment for AT (31 percent), followed by Medicaid (26 percent) and Medicare (19 percent).</li> </ul>	55

<b>Key Findings</b>	<b>Page</b>
<ul style="list-style-type: none"> <li>Healthcare providers are the principal source of information about AT (62 percent).</li> </ul>	59
<ul style="list-style-type: none"> <li>Respondents were much more likely to learn about “medically necessary” devices from their healthcare providers than to learn about other devices essential for participation and independence.</li> </ul>	64
<ul style="list-style-type: none"> <li>The principal problems people had with their AT related to the need for additional equipment (24 percent), repairs taking too long (22 percent), and a time delay in getting equipment (21 percent).</li> </ul>	69
<ul style="list-style-type: none"> <li>Abandonment of AT was reported infrequently, with only 20 percent having stopped using their equipment for any reason, generally because their condition changed or the device stopped working.</li> </ul>	72
<b>The Benefits of Assistive Technology</b>	
<ul style="list-style-type: none"> <li>There is a high level of overall satisfaction with assistive technology, with 70 percent of devices receiving a 4 or 5 on a five-point satisfaction scale.</li> </ul>	80
<ul style="list-style-type: none"> <li>Scooters, ventilators, and adapted telephones were the devices rated the highest in terms of satisfaction, and hearing aids and computers were rated lowest.</li> </ul>	82
<ul style="list-style-type: none"> <li>Respondents of all ages used AT to engage in a wide variety of activities in the community and at home, but younger respondents were much more likely than older respondents to use AT to engage in social, recreational, educational, or economic activities.</li> </ul>	89
<ul style="list-style-type: none"> <li>Devices regarded as most helpful to respondents in living independently included computers, adapted or ordinary vehicles, scooters, and electric wheelchairs.</li> </ul>	90
<ul style="list-style-type: none"> <li>The vast majority of respondents (72 percent) experience feelings of social isolation at least some of the time. One-third (33 percent) of respondents feel isolated due to their disabilities most of the time or always.</li> </ul>	92
<ul style="list-style-type: none"> <li>Respondents who had all the assistive technology they needed had half the level of social isolation of those with unmet need for AT (44 versus 23 percent experiencing frequent social isolation).</li> </ul>	96
<ul style="list-style-type: none"> <li>The vast majority of AT-using respondents said that their AT was helpful in reducing social isolation.</li> </ul>	97

## Key Findings

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### Assistive Technology in the Workplace

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- Only one-fifth (20 percent) of working-age respondents were employed, whether in full-time or part-time jobs or in self-employment. Only 6 percent had full-time jobs. 103
  - Of those who worked, 44 percent used some type of assistive technology to perform their work tasks, 23 percent made use of workplace accessibility features such as ramps and ergonomic furniture, and 20 percent used assistive services, such as job coaches, assistants, readers, or interpreters. 107
  - Use of workplace AT more than doubled with educational attainment—only 29 percent of working respondents with no college education used workplace AT, compared to 64 percent of those with graduate or professional degrees. 109
  - Computer technology was cited by the greatest number of respondents (22 percent) as being most helpful in getting or keeping a job. 110
  - More than two-thirds (68 percent) of respondents using AT at work reported that their AT helps them “a lot” or “immensely” in performing their work duties. 111
  - Specific benefits of using AT on the job include improved productivity (85 percent of respondents using AT work), improved self-esteem (72 percent), and better attendance (59 percent). 111
  - Employers and employees are about equally likely to have paid for AT used in the workplace (42 and 39 percent, respectively). Other payers include California Department of Rehabilitation (26 percent) and health insurers (20 percent). 113
  - Only 30 percent of employed respondents had ever asked for AT as a job accommodation. Of those who did ask, a majority (60 percent) got their request approved, and very few of the requests were denied outright (7 percent). 114
  - Lack of assistive technology was not seen as a major barrier to employment, with only 11 percent of all respondents citing this as a problem limiting them from working to their fullest ability. In contrast 76 percent cited “my disability” as a barrier. 116
-



Based on findings not only from the survey, but also from numerous detailed interviews with consumers and key AT stakeholders, we have developed a vision of what we consider to be the ideal AT system. Our vision is summarized as follows (for details, see page 115):

*Individuals who acquire disabilities, whether at birth, during childhood, adulthood or as a senior, will be made aware of technology that could help them, and asked about their need for equipment by a variety of medical and community service providers at key points in their relationship with that provider. Information specific to their need for devices will be offered, and evaluations for equipment will be available on a regular basis. Minority communities must not be left out when it comes to finding out about and getting AT; that is also true for certain disability groups such as those with cognitive or mental health disabilities. People with disabilities must be involved in the development of equipment and in making funding decisions. Funding for equipment needs to be readily available, as do opportunities for trying out equipment, for talking to others who use it, and for obtaining refurbished equipment from a recycling program, donated by people who no longer need it. Training and maintenance services will be offered and available, as well as upgrades and replacement. To do less than this means that individuals with disabilities will experience a loss of independence, diminished economic participation and increased social isolation at various times in their lives.*

# Chapter 1

## Background

In 2001, the California Foundation for Independent Living Centers (CFILC) received a five-year research grant award (#H133A010702) from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, to look at the effectiveness of assistive technology for people with disabilities. We started with a literature review which, in 2002, resulted in a book, *Is It Working? A Review of AT Successes and Barriers*. Next, we conducted qualitative research through focus groups with people with disabilities across California (see specifics below) and presented those findings in 2004 in a second book, *How It Works: AT Narratives from California*. In the fourth year of the project, we conducted two major activities: action teams tackled several projects to improve access to AT, based on the focus groups suggestions and findings from a preliminary survey; and a major quantitative survey was sent out to a random sample of consumers from 20 Independent Living Centers (ILCs) across California. A separate monograph on the action team activities is available. This book presents the findings from the quantitative survey. All of the research products from this grant can be found on the CR4AT website, [www.cr4at.org](http://www.cr4at.org), with principal publications available in both English and Spanish.

### Methods

This project used Participatory Action Research (PAR) to explore the question, “Is Assistive Technology effective for people with disabilities in the areas of health, employment, function, Independent Living and community integration?” PAR is a research philosophy in which the populations under study (in this case, people with disabilities) are essential participants in all phases of the research, including the formulation of research questions and the interpretation of findings. Proponents of PAR believe that this approach strengthens the relevance of the research to the population under study and increases the likelihood that the findings will be of value in advocating for policy change. The focus on both active participation of the population being researched and the practical objectives to be achieved resonates strongly with the principles of the Independent Living Movement, in which people with disabilities are empowered to make their own choices and work to achieve societal change.

### Survey Development

The survey that forms the basis for this research was developed in a collaborative process between researchers, people with disabilities and AT Advocates (see Appendix B). An initial list of research

questions developed by the project team was narrowed using a survey of key informants, including independent living center directors and assistive technology advocates, and a series of preliminary focus group interviews with stakeholders, including people with disabilities, employers, and AT vendors and manufacturers.

After the topics of highest priority were identified, focus groups of AT users were held throughout California to discuss those topics. Forty-three focus groups involving 333 participants were held, each lasting between 90 minutes and two hours. Recruitment for some groups targeted specific racial or ethnic minority groups (Spanish speakers, African Americans, Native Americans, or Asian Americans), while others targeted specific disability populations (deaf or hard of hearing, blind, seniors, people with cognitive disabilities, people with mental health disabilities, or those with speech impairments) or people living in rural areas of the state. As part of the participatory nature of the project, focus groups were led by community-based advocates, many with disabilities, who had undergone training in conducting such interviews.

Focus group leaders worked in tandem with the research team to analyze transcripts of the interviews to extract common themes. Some of the key themes involved the importance of AT in the lives of its users, supporting their ability to live independently and to participate in society, while other themes

dealt with other aspects of life not directly related to AT, such as the need for accessible transportation, accessible housing, personal assistance services, and enough financial resources to get by. AT-specific themes included difficulties encountered when equipment broke or needed repair, aesthetics, portability, ease of use, and need for greater consumer choice.

The project then shifted into the quantitative arena. Based on the focus group themes, the team worked to develop a 66-item questionnaire, focusing on the use of AT in the home, community, and work, as well as the problems and benefits of AT. Additional questions dealt with health care access issues, income sources and amounts, and general demographics. This instrument was then pilot tested in multiple modes. Paper questionnaires were handed out at independent living centers throughout California, with in-person or telephone interviews offered as accommodations to those unable to complete the written survey. In addition, participants in disability-related listservs and email lists, as well as visitors to an assistive technology web site, were invited to complete the survey over the Internet. Despite considerable efforts to recruit AT users, only 327 respondents completed the pilot survey in all modes; many others began the online survey, but did not finish it.

Based on both the experience of conducting the pilot and the responses collected, extensive changes were made

to both the questionnaire and the survey procedures. As a result of the difficulty in recruiting respondents, the high rate of missing responses to some items, and the apparent exclusion of respondents with lower educational attainment, the instrument was shortened and its language and structure simplified to make it easier to get complete responses by a broader audience.

## Survey Procedures

Most importantly, the survey procedures were modified to both increase the response rate and to allow for measurement of that rate. In the full survey, the paper questionnaire was offered as the primary response mode, with telephone or Internet response available as accommodations. Independent Living Centers throughout California were recruited to participate, and 20 of the 29 ILCs in California did so by mailing out questionnaires to a random sample of consumers (current or former Center users) listed in their databases. These ILCs included a balance of the northern and southern parts of the state, of urban, suburban, and rural areas, and of Centers serving various minority populations.

Respondents could choose to fill in the questionnaire and mail it back, call the CFILC office and complete the survey over the phone with a trained staff member, or complete the survey over the Internet. An incentive of \$20 was offered to each respondent for his or her participation, and an additional \$10 was offered to the ILC for each consumer

responding. To prevent duplicate responses from a single individual, a unique code was supplied with the mailed questionnaire and was requested from the respondent during survey completion. A reminder postcard was mailed out a few weeks following the initial mailing.

Of the 14,104 questionnaires mailed out (less the 1,026 returned as undeliverable), 1,919 people responded to the survey in all modes, for a response rate of 14.7 percent. This rate varied considerably by ILC, perhaps depending as much on database quality as on population demographics, from a high of 20.5 percent in Eureka to a low of 4.4 percent in East Los Angeles (see Appendix A). By focusing exclusively on ILC users, we were able to assemble a large and diverse pool of people with disabilities throughout California, but we make no claims that our sample is representative of the experiences of all Californians with disabilities.

## Data Analysis

Following completion of the data collection in the fall of 2005, a team of researchers and disability advocates spent the fifth year of the project collaboratively performing a careful analysis of the responses to the survey. The charts, tables, and statistics presented in this book represent our principal findings; presented in a way we hope will be useful to advocates, policy makers, and consumers. Although the data we present here are primarily based on tabulations and cross-tabulations of responses to

survey questions, we have also performed more elaborate statistical analyses aimed at capturing a more nuanced picture of AT usage. Those findings are being presented at academic conferences and in journal publications.

## Findings

In Chapter 2, we present data characterizing the respondents to the CR4AT survey, highlighting their diversity in terms of disability status, age, race, and ethnicity, their very low income levels, and the multiplicity of daily activities they engage in. Chapter 3 presents data on the various kinds of technology people use and how much, as well as differences in device usage between: people with different types of disabilities, age groups, racial and ethnic groups, educational backgrounds, and income levels.

Chapter 4 presents data on unmet need for AT, problems with the devices people use, and the barriers to AT acquisition, the most important of which are financial and informational. Data on the benefits that AT users get from using their technology are presented in Chapter 5. Users report high levels of satisfaction with the majority of their devices, most likely because the devices allow them to engage in a wide range of home and community activities, reducing their degree of isolation and allowing greater participation.

Usage of assistive technology in the workplace is the focus of Chapter 6, including the devices people use, the benefits of using devices, source of

payment for AT at work, and outcomes of accommodation requests. Data are also presented on the use of assistive services, such as interpreters, readers, and job coaches, and of accessibility features, such as ramps and elevators. Finally, drawing from all of our survey and focus group findings, Chapter 7 offers our vision of an ideal system for making assistive technology available to all consumers who could benefit from it.

## Chapter 2

# Characteristics of the CR4AT Survey Respondents

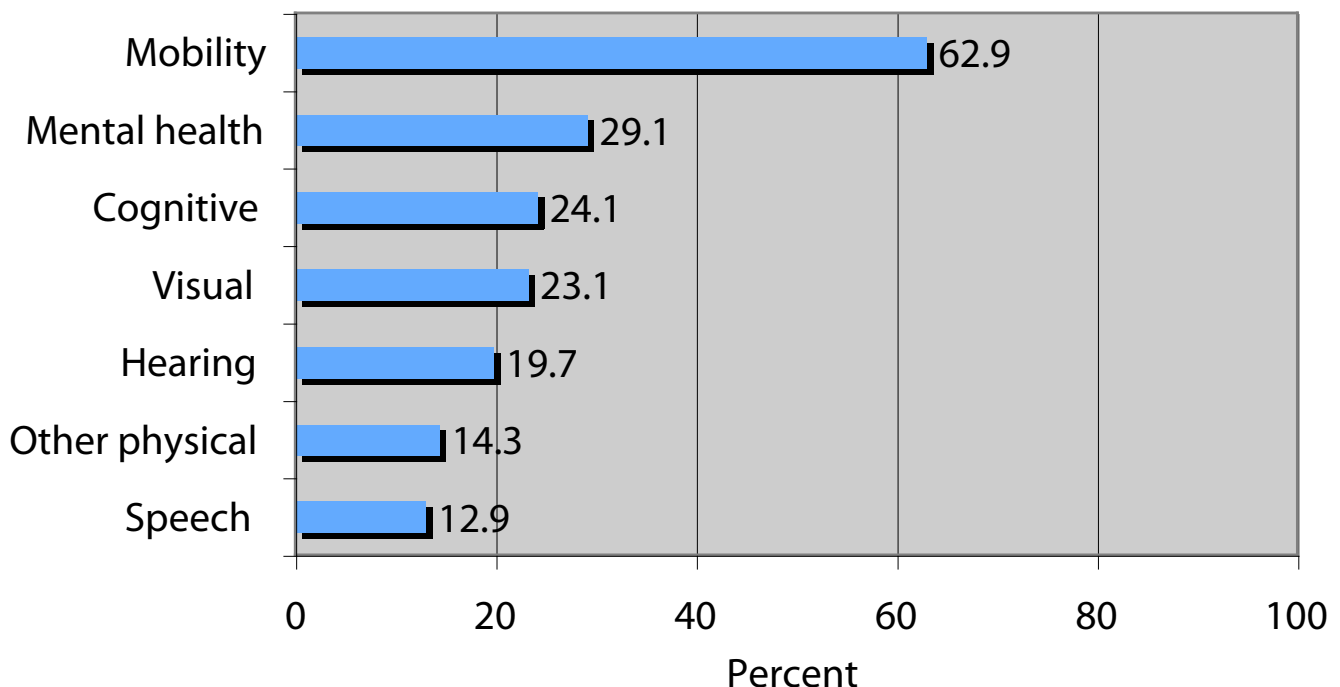
### Disability type and severity

Survey respondents were given a checklist of twelve statements related to functional limitations and asked to mark all that applied. The statements referred to **sensory limitations** (“I am blind,” “I have low vision,” “I am Deaf,” and “I am hard of hearing”), **speech impairments** (“I don’t speak,” and “People have trouble understanding me when I speak”), **mobility impairments** (“I can’t get around without help or equipment,” and “I have trouble walking or am limited in mobility”), **cognitive limitations** (“I have mental retardation,” “I have a developmental disability,” or “I have a learning disability”),

and **mental health disabilities** (“I have a mental health or psychiatric disability”).

A final option was to check the statement, “I have some other type of disability,” and to specify it. Respondents selecting this statement often named chronic illnesses or mentioned pain, fatigue, or general poor health, all of which we classified as “other physical disabilities.” Other conditions, which we added to the “mobility impairments” classification, included various musculoskeletal conditions, such as back pain or arthritis, limitations in using the arms or hands, paralysis, and other specific conditions limiting mobility. Responses mentioning a

**Type of disability among CR4AT respondents**





brain injury or a specific cognitive limitation were classified along with other cognitive disabilities from the checklist. Specific vision- or hearing-related conditions were classified along with the visual or hearing impairments from the checklist. Mentions of specific mental health diagnoses were classified along with mental health disabilities from the checklist.

In all, 96 percent of respondents identified at least one type of disability. A majority of respondents (55 percent) identified more than one type. The chart shows the prevalence of each type of disability in our sample, with people with multiple disabilities appearing in multiple categories. Some 63 percent of respondents report some level of mobility impairment, the most common type of disability. Next are mental health disabilities, at 29 percent of the sample. Cognitive and visual impairments are each reported by about one-quarter of the sample, and hearing impairments by one-fifth. Some 14 percent report other physical impairments, and 13 percent have speech impairments.

Although we are able to distinguish between more and less severe levels of impairment in several categories, small sample sizes often limit our ability to make detailed comparisons between groups. For example, only 47 respondents (less than 3 percent of the sample) identified themselves as Deaf, only 74 as blind (4 percent), and only 65 respondents were identified as having an intellectual disability (3 percent checked “mental retardation”).

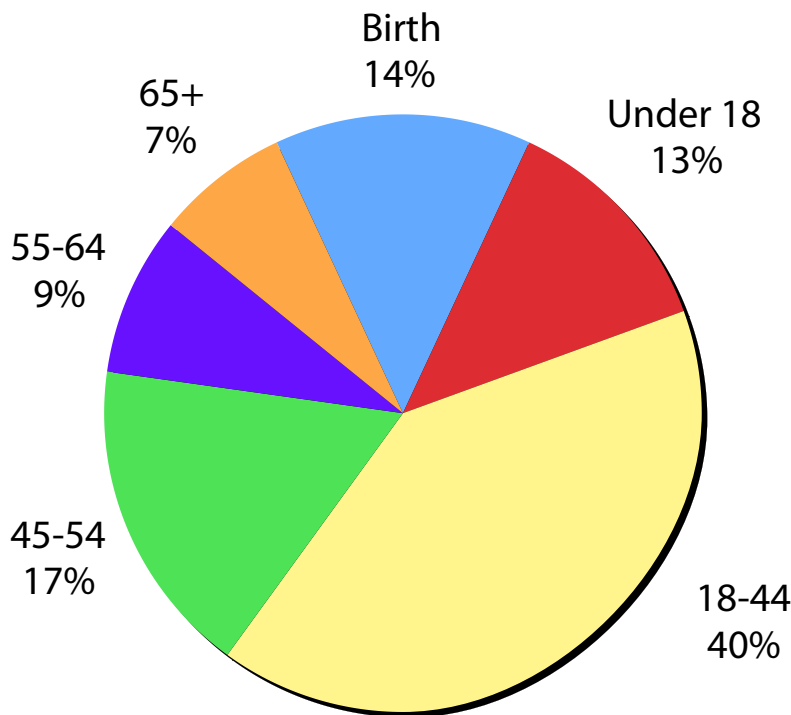
A substantial minority of respondents (38 percent) have disabilities severe enough that

they require personal assistance with daily activities. Thirteen percent get informal help from family members, 19 percent get formal help from paid attendants, and 6 percent get both formal and informal help.

## Lifelong versus acquired disability

Only a small minority of CR4AT respondents had lifelong disabilities, with 14 percent stating that they had acquired their disability at birth. A further 13 percent acquired their disability during their childhood. The vast majority of respondents reported that their disability began during their adult years; with 40 percent acquiring their disability between the ages of 18 and 44, 26 percent between 45 and 64, and only 7 percent reported the onset of disability at age 65 or later.

**Age of disability onset**



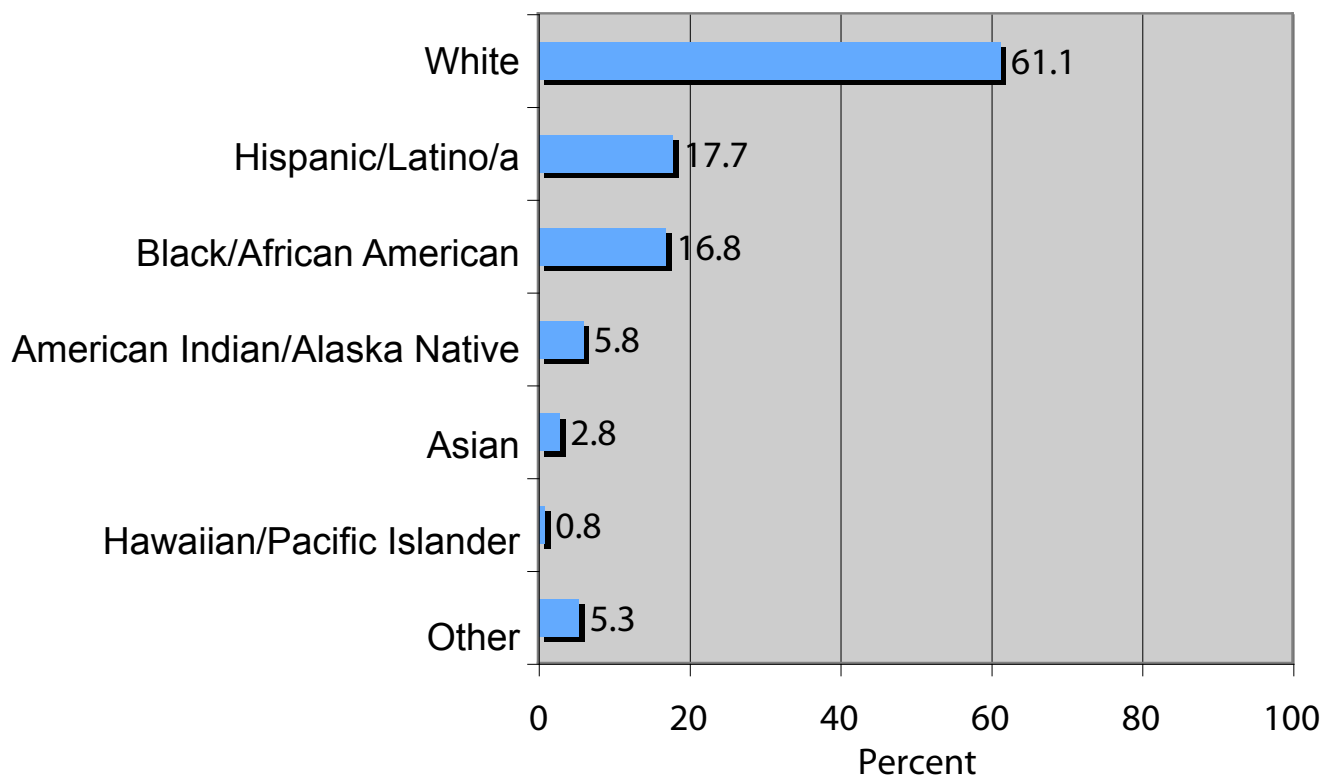
## Age, gender, race and ethnicity

Only adults 18 years of age or older were invited to participate in the survey.<sup>2</sup> About four-fifths of respondents (81 percent) were under 65, with 28 percent between the ages of 18 and 44, 29 percent between 44 and 54, and 24 percent between 55 and 64. About one-tenth (9 percent) were between 65 and 74 years of age, and another tenth (10 percent) were 75 or older.

Far more women than men responded to the survey (61 versus 39 percent). Small numbers of respondents identified as transgender (5 respondents, or 0.3 percent) or intersex (4 respondents, or 0.2 percent), both of which were offered as response categories.

The racial and ethnic background of the CR4AT respondents showed substantial diversity. Respondents were offered six racial/ethnic categories, plus “other,” and asked to mark as many as applied. Some 61 percent checked white (possibly along with some other category), 18 percent identified as Latino or Hispanic (again, possibly but not necessarily in combination with a racial category), and 17 percent as black or African American. Just over 100 respondents (6 percent) identified as American Indian or Alaska Native, 51 respondents (3 percent) as Asian, and only 14 respondents (less than 1 percent) as Hawaiian or Pacific Islander.

**Race/ethnicity of survey respondents**



<sup>2</sup> Survey research involving children is cumbersome because of the legal requirement that either parental approval be obtained or the parents be allowed to answer on behalf of their children.

## Education and Income

About one-quarter (26 percent) of CR4AT respondents had college degrees, and an additional 36 percent had attended some college. Most of the rest (38 percent of all respondents) had high school diplomas; only 18 percent of respondents were not high school graduates.

These figures indicate a slightly higher level of educational attainment than among the general California population, according to 2005 data from the Census Bureau's American Community Survey. Some 62 percent of the CR4AT sample either graduated from college or attended without graduating, compared to 57 percent of the California adult population.

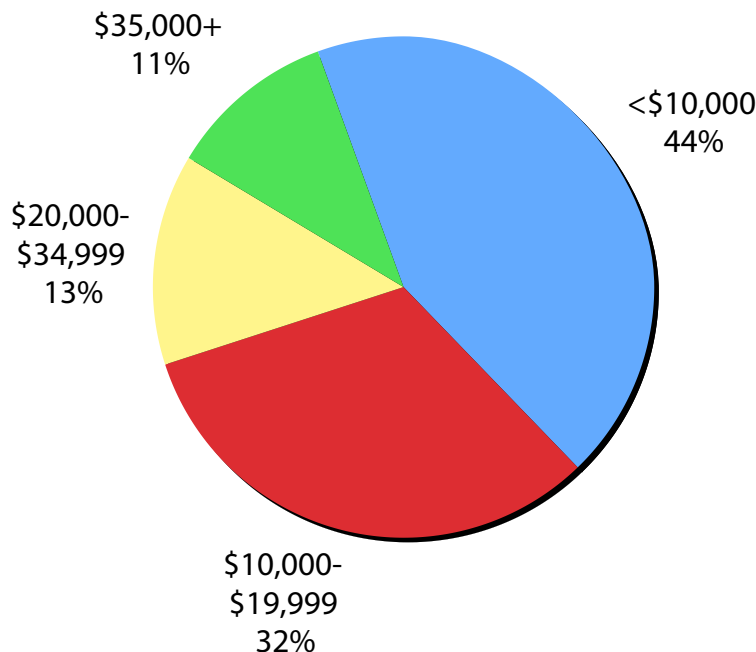
Despite being fairly well educated, the typical CR4AT respondent lives in relative poverty. More than three-quarters of the

respondents (76 percent) have annual household incomes of less than \$20,000. In contrast, only 17% of California households live on less than \$20,000 per year, according to the American Community Survey.

A still more striking statistic is the 44 percent of CR4AT respondents who subsist on less than \$10,000 in annual household income. Only 7 percent of California households have incomes this low. At the opposite end of the spectrum, only 11 percent of our respondents reported household incomes of \$35,000 or greater, a level achieved by two-thirds (67 percent) of California households.

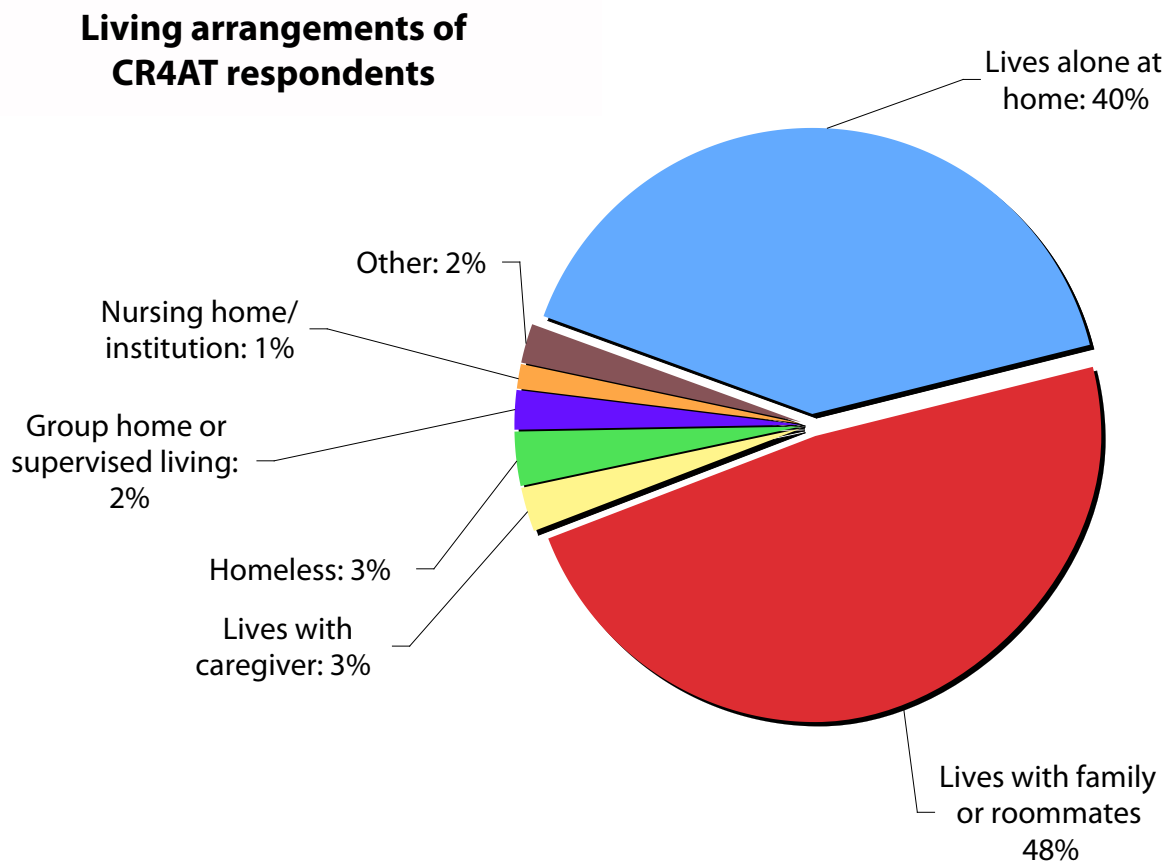
The vast majority of respondents (71 percent) reported federal benefit programs as a major source of income, followed by earnings (15 percent) and retirement income (14 percent).

**Annual household income of CR4AT respondents**



## Living arrangement

The vast majority of respondents live independently in community settings, with only 1 percent of respondents living in nursing homes or other institutional settings and 2 percent living in group homes or other supervised environments. Some 40 percent of respondents live alone, 48 percent live with family members (spouse, parents, children) or roommates, and 3 percent have live-in caregivers. Homelessness was reported by 3 percent of respondents.



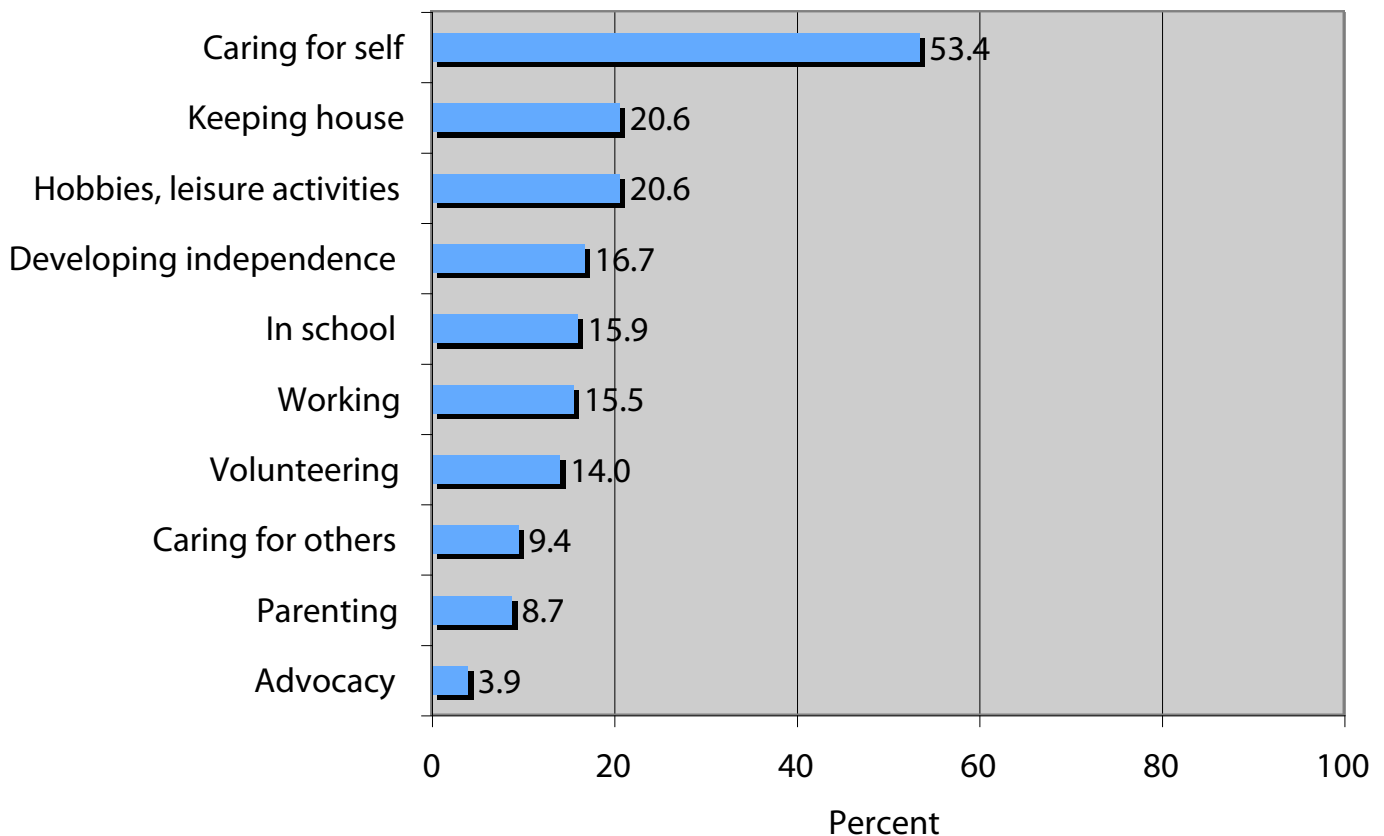
## Major activities

When respondents were asked to identify their major activities from a list of ten items, with multiple responses permitted, far more chose “caring for myself” (53 percent) than any other activity. In a tie for a distant second place were “keeping house” and “hobbies and leisure activities,” both selected by 21 percent of respondents. Next were “developing independence” at 17 percent and “in school” and “working,” both at 16 percent, and “volunteering” at 14 percent. “Caring for others,” “parenting,” and “advocacy” were the remaining choices, with advocacy selected by only a very disappointing 4 percent of respondents (and remember

that these are Independent Living Center consumers who, by virtue of that connection, have some association with the independent living movement).

When limited to working-age adults, “working” increases in prominence as a major activity, but only slightly, to 18 percent. A few other respondents have jobs (generally part-time or self-employment) that they do not regard as major activities, bringing the total rate of employment up to 20 percent, as further discussed in Chapter 6. Only 13 percent of respondents who were not working said that they were looking for work.

**Major activities among CR4AT respondents**





## Conclusions

Randomly selected from among the adult consumers served by Independent Living Centers throughout California, the people who responded to the CR4AT survey are highly diverse in terms of age, race, ethnicity, and type of disability. A majority of respondents reported multiple disabilities, and many had disabilities severe enough to require personal assistance. Relatively few had life-long disabilities, with most acquiring their disability in adulthood. Most live in the community, either alone or with family members or in shared households. Though their educational attainment is relatively high, income levels are quite low. Most subsist on some form of disability benefits, and very few have jobs. Respondents nonetheless engage in a great variety of personal and community activities.

In terms of their diversity, relative poverty, and low rate of employment, we believe that the CR4AT respondents represent typical California ILC consumers, and we hope that their experiences summarized in this report reflect those of the segment of the disability population served by these Centers throughout the state.

## *Chapter 3*

# **AT Usage and Disparities**

People with disabilities use a wide range of assistive technology to help carry out their daily activities. About two-thirds (66 percent) of our sample of California Independent Living Center consumers reported using one or more AT devices, with about half (49 percent) using multiple devices.

Usage of assistive technology is far from uniform within our sample, however. People with mobility or sensory disabilities are far more likely to use AT than those with cognitive or mental health disabilities, for example,

and older consumers are far more likely than younger adults to do so. In addition to differences in overall usage, there are also differences in usage of specific devices; for example, older respondents report much more use of low-tech devices than younger respondents, and younger respondents use far more high-tech devices than older respondents. Usage also varies with age of disability onset, race and ethnicity, educational attainment, and family income.

## What devices do people use?

Respondents were given a checklist of 22 popular AT devices and asked to identify all those they currently used, as well as to write in the names of any additional devices not on the list. The low-tech mobility device category of canes, crutches, or walkers was by far the most prominent response, with 34 percent of respondents using such a device. Next was manual wheelchairs, at 19 percent, followed by off-the-shelf computers, reachers/grabbers, and electric wheelchairs, each used by between 13 and 15 percent of the sample. Other frequently mentioned devices were magnifiers, adapted telephones, and hearing aids.

In contrast to the relatively heavy usage of equipment for people with mobility impairments, hearing loss, or low vision, usage rates of devices for people with less prevalent disabilities, such as deafness or blindness, were much lower. For example, only about 2 percent of respondents used a white cane or a TTY, and only 1 percent used a communication device such as a speech synthesizer.

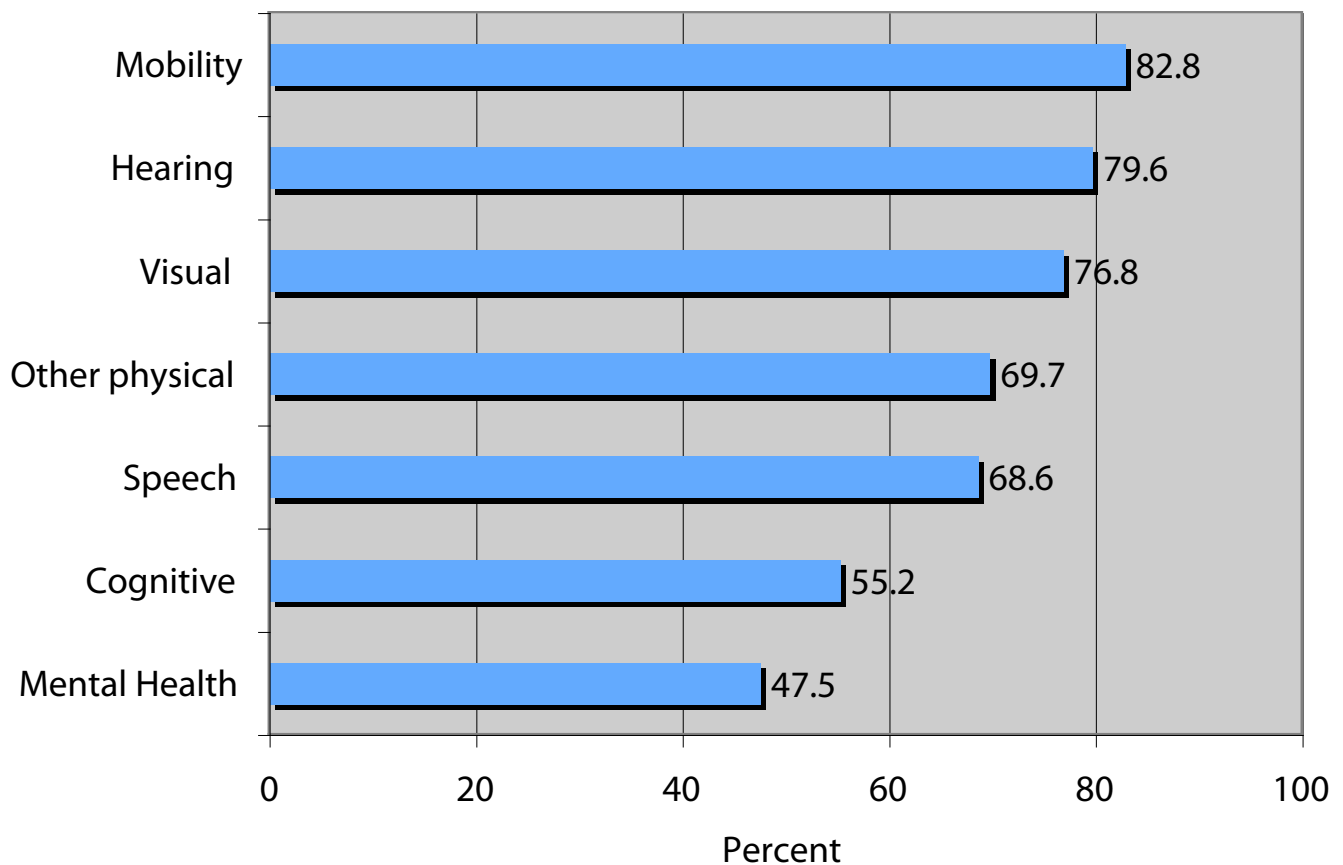
Devices that were not included on the checklist but were mentioned by respondents included prostheses, braces, bathroom or shower chairs, grab bars, eyeglasses or lenses, breathing machines (CPAP/BiPAP), and ergonomic furniture.

Usage of AT devices among the CR4AT sample	
Device	Percent
Cane, walker, or crutches	34.0
Manual wheelchair	18.7
Computer (off the shelf)	14.6
Reacher / grabber	13.6
Electric wheelchair	13.1
Magnifiers	11.0
Adapted telephone	10.7
Hearing aid	8.6
Books on tape	7.5
Scooter	6.3
Specialized software	6.2
Oxygen	5.3
Adapted Vehicle	4.8
Adapted eating/cooking utensils	3.5
Specialized hardware	3.2
Flashing/vibrating alerting device	3.0
Talking devices	2.6
White cane	2.2
Relay services	2.2
Ventilator	2.1
TTY / text pager	1.5
Communication device	1.0
Other	20.9
Any AT device(s)	66.4

## How does AT usage vary by disability type?

More than four-fifths of respondents with mobility impairments (83 percent) reported using some type of assistive technology, more than any other disability group in our sample. Nearly as likely to be using AT were respondents with hearing impairments (80 percent) or visual impairments (77 percent). The disability groups with the lowest AT usage were those with mental health disabilities (48 percent) and those with cognitive disabilities (55 percent).

**Assistive technology usage, by disability type**



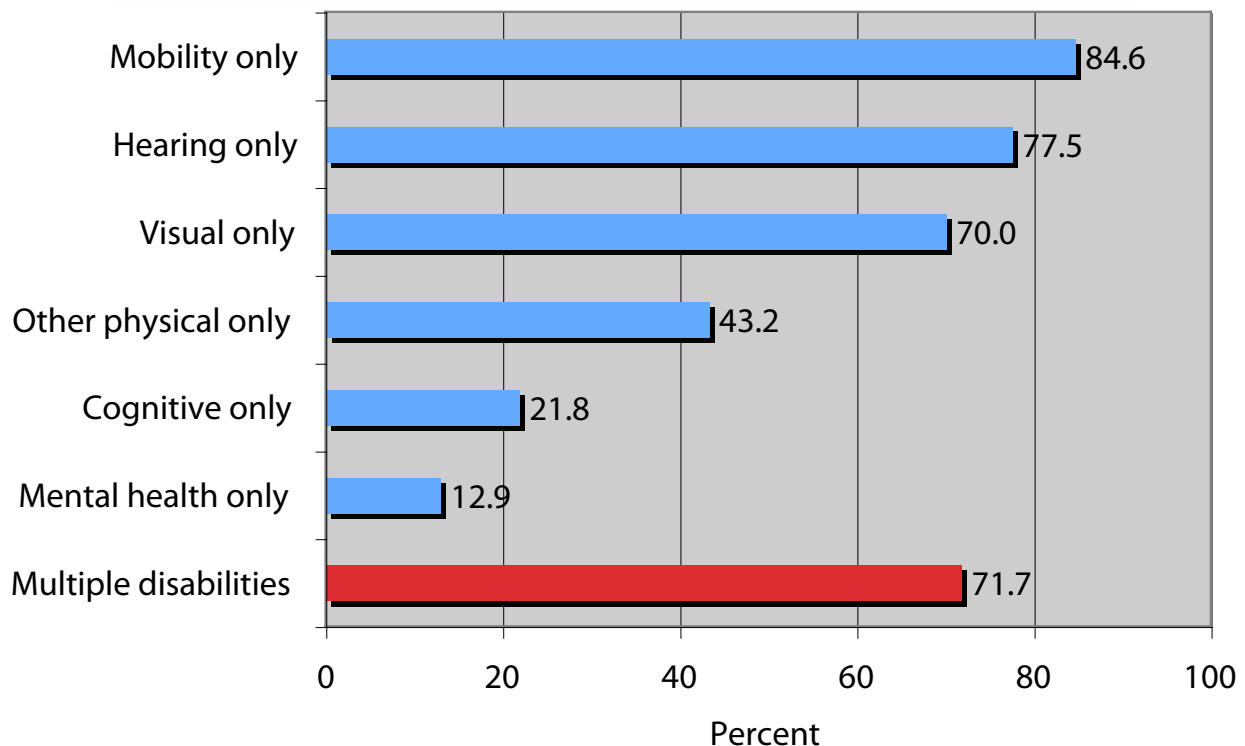
## Usage among people with single and multiple disabilities

Many of our respondents reported more than one type of disability, meaning that the disability categories in the previous chart are not mutually exclusive. For example, quite a few respondents with mobility impairment also had some type of sensory impairment or a mental health disability. Because multiple disabilities are common, AT usage rates for some disability types might have been inflated in the previous chart because some people in that grouping might have been using AT for some other co-occurring disability.

This chart has disability categories that are mutually exclusive, with respondents categorized according to either the single type of disability they have,<sup>3</sup> or into the

category “multiple disabilities.” Here we see much more clearly that usage of AT for mental health or cognitive disabilities is extremely low: only 13 percent of people reporting a mental health disability (and no other disability) used any kind of AT, and only 22 percent of those with a cognitive disability (and no other disability) used AT. At the other end of the spectrum, technology for mobility or sensory impairments was extensively used by our respondents: Some 85 percent of respondents with a mobility impairment (and no other impairment) reported AT use, as did 78 percent of those with hearing impairment only and 70 percent of those with a visual impairment only.

**Assistive technology usage, by disability type**



<sup>3</sup> Only a handful of respondents reported a speech impairment without any other type of disability, and that category has been omitted from the chart.

## Extent of AT usage

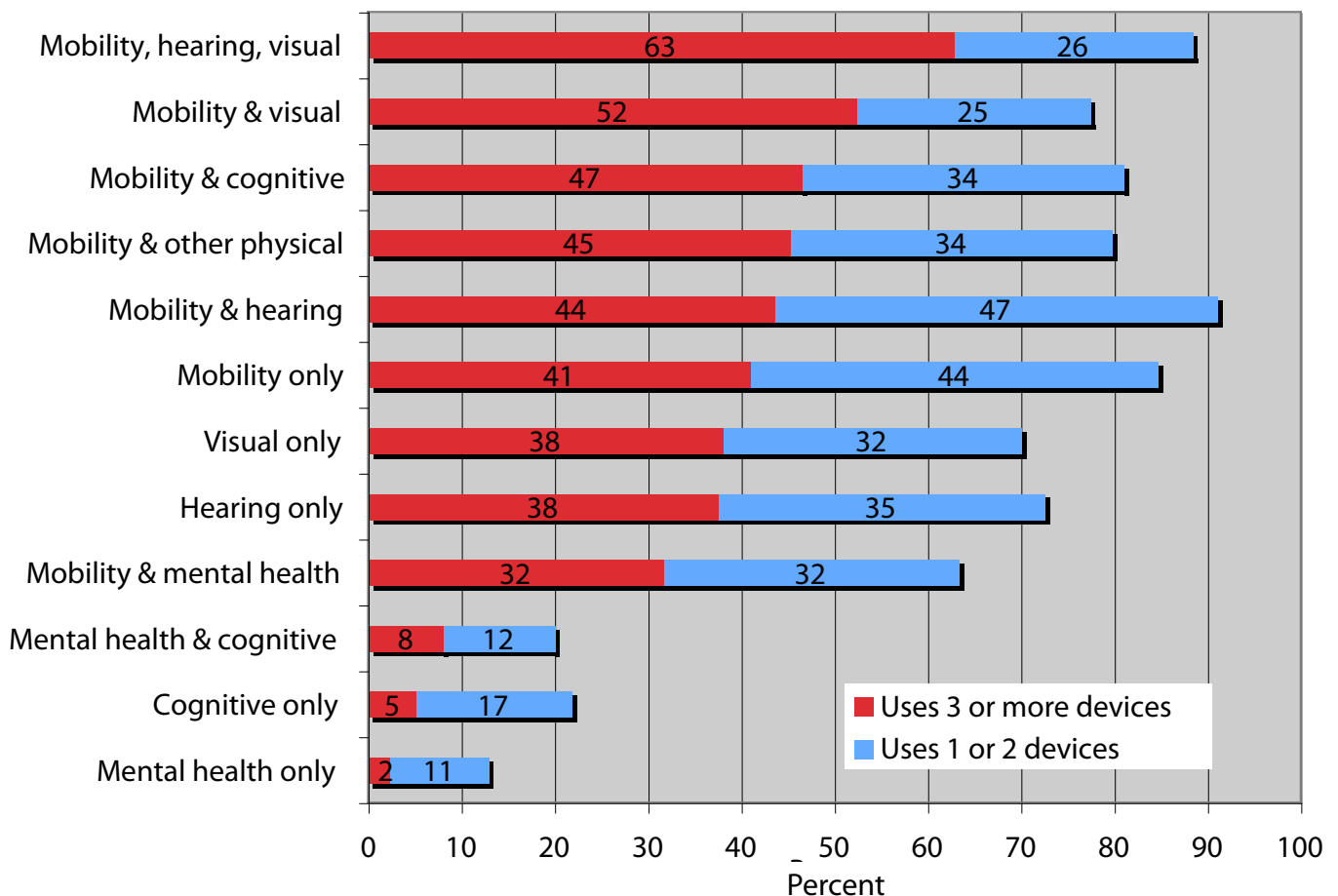
Some 35 percent of respondents could be said to be heavy AT users, in that they report using three or more AT devices. The rest use one or two AT devices (32 percent) or none at all (34 percent)

As shown in the previous chart, people with multiple types of disability are very likely to use some form of AT. In general, they are also heavy AT users, often using separate devices for the different types of disability they have. This chart shows the extent of AT usage among people with common patterns of disability, either a single type of disability or multiple types. A large majority (63 percent) of respondents who have a combination of mobility, hearing, and visual impairments are

heavy AT users, as are roughly half of respondents with mobility and visual impairments or mobility and cognitive impairments. Roughly 40 percent of people with only one type of mobility or sensory impairment are heavy AT users.

In sharp contrast to the relatively large proportions of respondents with mobility and/or sensory disabilities using three or more AT devices, heavy AT usage is reported by only 2 percent of respondents with mental health disabilities alone, only 5 percent of respondents with cognitive disabilities alone, and only 8 percent of those with both mental health and cognitive disabilities.

**Extent of AT usage among respondents with common disability patterns**

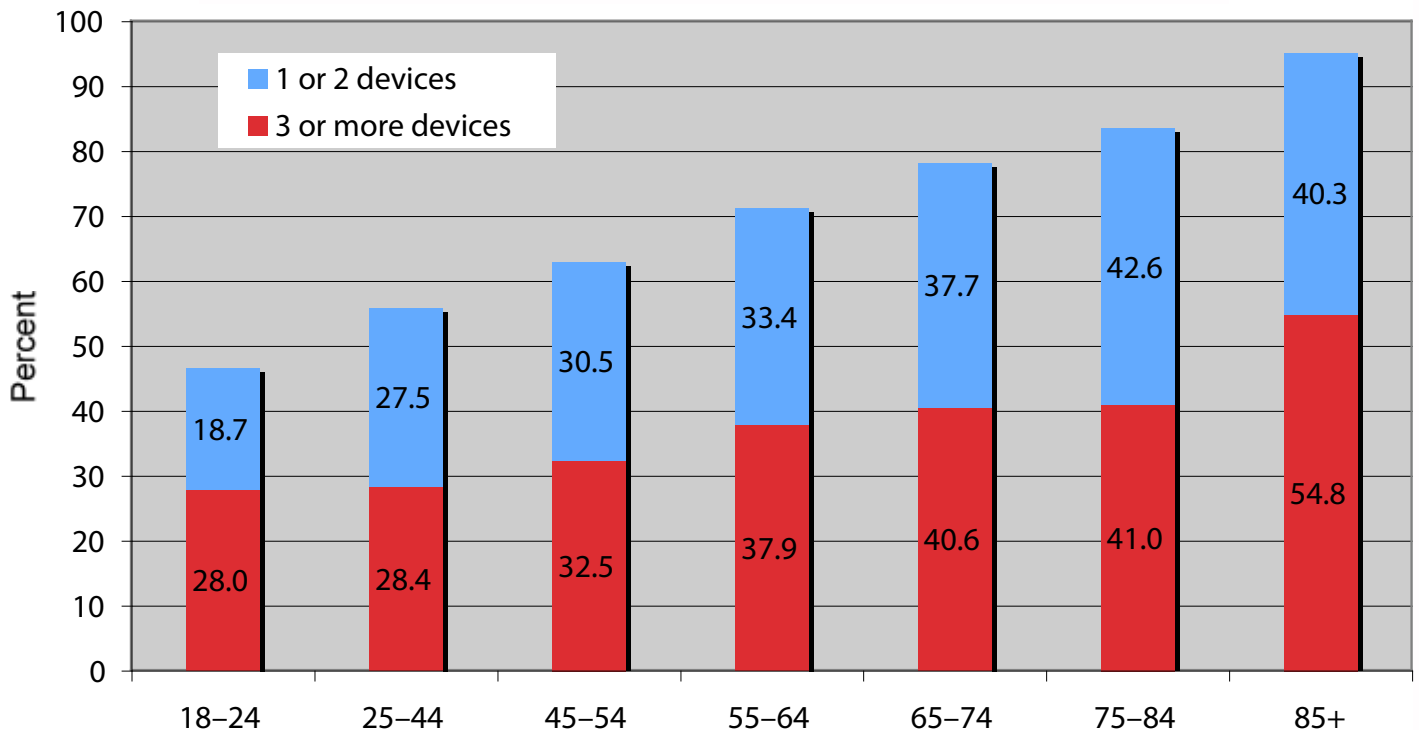


## How does AT usage vary by age?

AT usage steadily increases with age, with the proportion of respondents using AT doubling from the lowest to the highest age groups. Of respondents aged 18–24 years, 47 percent report AT usage, compared to 95 percent of respondents aged 85 years or older. One explanation is that older respondents are more likely than younger respondents to have mobility impairments, hearing loss, and low vision, types of disabilities for which people generally use assistive technology.

People who are 85 or over are also twice as likely to be heavy users of AT when compared to adults under 25, with 55 percent versus 28 percent using 3 or more AT devices.

**Extent of AT usage, by age group**



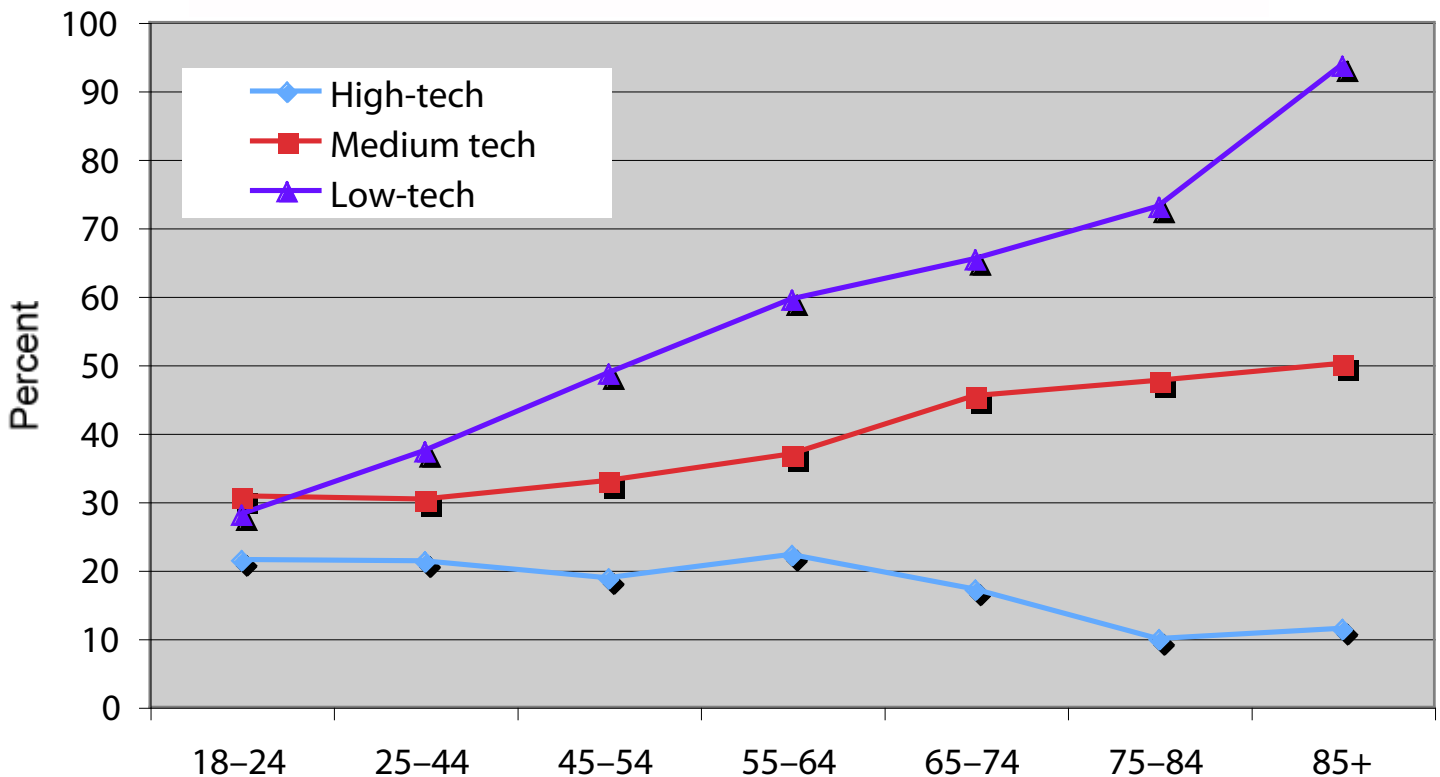
## Age and type of devices used

Not only does overall usage of AT vary considerably with age, but also the types of devices people use. When we separately consider usage of high-tech, medium tech, and low tech AT devices, we find substantially different patterns of usage depending on the age of the respondent. By high-tech devices, we mean any device using digital technology, such as a computer, special software or hardware, a communication device (speech synthesizer), or a talking device. We consider all other electronic or motorized devices to be medium tech (includes such devices as electric wheelchairs, scooters, hearing aids, TTYs, and adapted telephones). The remaining manual, non-electronic devices are classified

as low-tech, and include manual wheelchairs, walkers, reachers and grabbers, magnifiers, and white canes.

Usage of low-tech devices increases dramatically with age, with the rate more than tripling from 28 percent for the youngest age group (18–24) to 94 percent for the oldest group (85+). In sharp contrast, usage of high-tech devices among elderly respondents (about 10 percent for those 75 or over) is about half that of working-age respondents (roughly 20 percent). Usage of medium tech devices increases with age, but much less dramatically than for low-tech devices, from 31 percent for the youngest group to 50 percent for the oldest.

**Usage of high-, medium-, and low-tech assistive devices, by age group**





These findings suggest that there is a digital divide in assistive technology usage, just as there is in general technology usage, between elderly and younger adults with disabilities, and that seniors may be relegated to using old-fashioned, low-tech devices when powered or high-tech devices might serve them better.

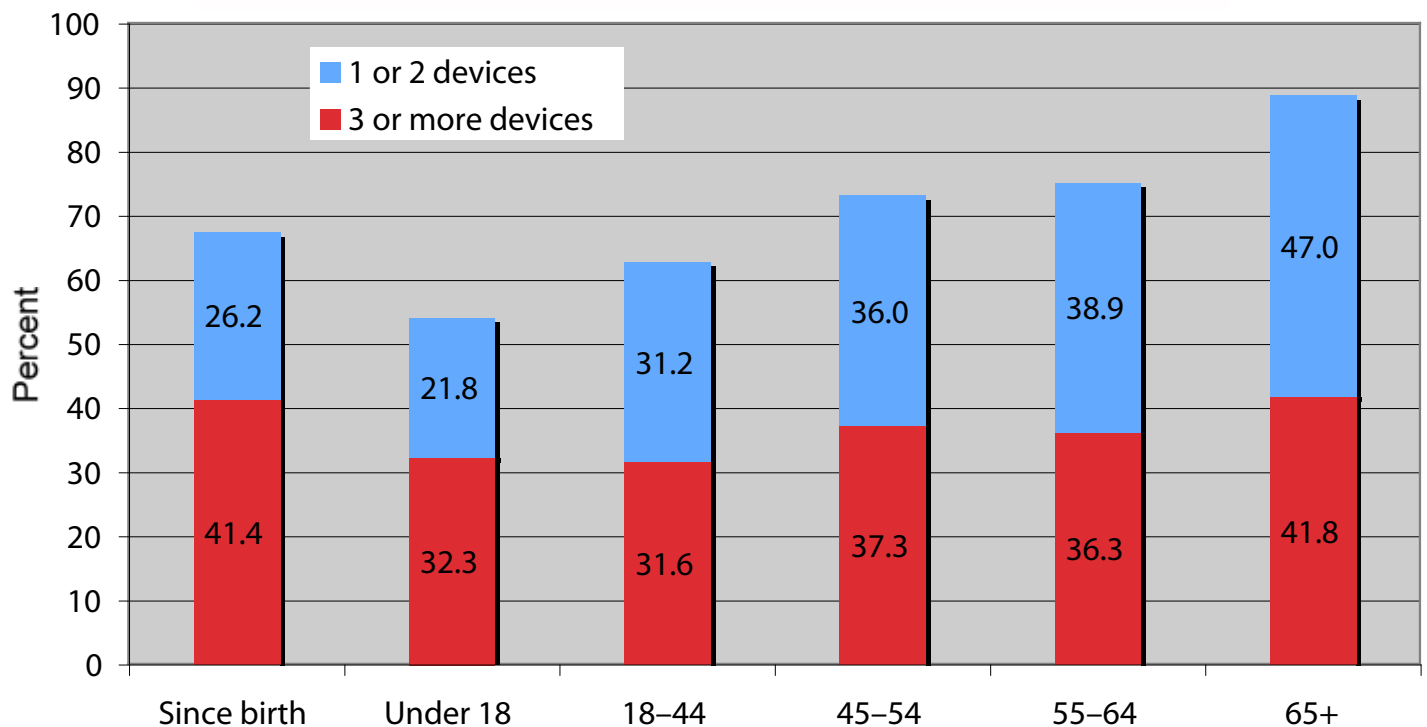
## How does AT usage vary by age of disability onset?

A person who has had a disability all of his or her life may have a very different relationship to assistive technology from someone who acquired a disability late in life. The age at which a person first acquires a disability may therefore be an important factor, separate from the person's age, in influencing whether or not they use any technology, and how much they use.

We find that, indeed, usage of AT does vary considerably with the age of disability onset. Respondents acquiring their disability at birth were more likely to use AT than those acquiring their disability in childhood or early adulthood (68 percent of those with birth onset use AT, compared to 54 percent with childhood onset and 63 percent with

onset between 18 and 44). Heavy AT usage (3 or more devices) is also more prevalent for those with birth onset (41 percent) than for those with onset in childhood or young adulthood (32 percent for both groups). Birth-onset disabilities, which are often fairly severe, may be more likely to require AT. Aside from possible differences in the nature of the disability, however, is the fact that people growing up with disabilities have access and exposure to assistive technology through the educational system, and may become accustomed to using AT at a very early age, after which it becomes an essential part of conducting daily activities. People with onset later in childhood or young adulthood may lack such resources and may not adapt to AT as easily.

**Extent of AT usage, by age of disability onset**



People acquiring their disability at age 45 or after also have higher rates of using AT than those with onset in childhood or young adulthood. The highest rate of AT usage is among those with onset after age 64, at 89 percent. That group also has a high rate of heavy AT usage (42 percent using 3 or more devices), just above that of people with birth onset. People with elderly-onset disabilities may have multiple mobility and/or sensory impairments requiring more devices, and they tend to have either their own financial resources—often following decades of disability-free employment—or access to certain assistive devices through Medicare.

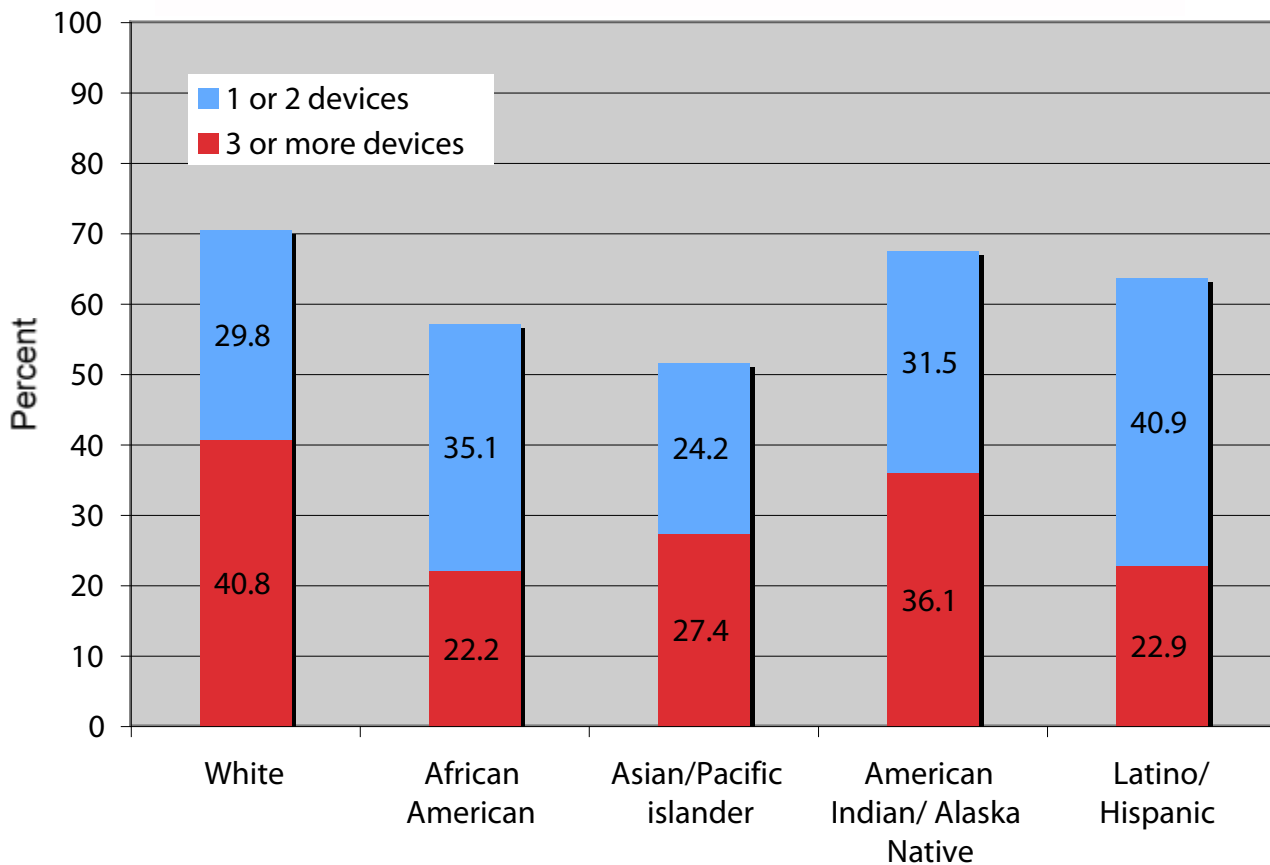
## How does AT usage vary by race/ethnicity?

Among the Independent Living Center consumers we surveyed, there were substantial disparities in AT usage by race and ethnicity. Both African Americans and Latinos were significantly less likely to use any assistive technology than their non-minority counterparts. Only 57 percent of African Americans and 59 percent of Latinos reported using any type of AT, compared to

71 percent of whites.<sup>4</sup> Even more striking are the disparities in heavy usage of AT: only 22 percent of African Americans and 23 percent of Latinos reported using 3 or more AT devices, compared to 41 percent of whites.

Asians and Pacific Islanders also reported significantly lower overall AT usage than whites (52 versus 71 percent using any kind

**Extent of AT usage, by race/ethnicity**



<sup>4</sup> Respondents were presented with a list of racial/ethnic groups (white, Hawaiian/Pacific Islander, Black/African American, Asian, American Indian/Alaska Native, Hispanic/Latino/a, and other) and asked to check off as many as applied. The Asian and Hawaiian/Pacific Islander categories were combined in the analysis because the latter category had few respondents; the category “other” also had few responses and has been omitted from the analysis. Because of multiple responses, racial/ethnic categories in the chart are not mutually exclusive. Hispanic ethnicity is technically distinct from racial identity, but it was up to Latino respondents to decide whether or not to check both a racial category and Hispanic/Latino.

of AT), but the small sample size for this population (62 respondents) makes us reluctant to draw conclusions from this finding. Similarly, the fact that we find no statistically significant difference in AT usage between American Indians and whites (68 versus 71 percent) may also be due to the small sample size (108 respondents) for this minority group.

As for the observed lower usage levels among African Americans and Latinos, there are several possible explanations. Lower usage could be the result of other demographic factors not directly related to race, such as lower average age or educational attainment, both of which are associated with lower AT usage (as shown elsewhere in this chapter), or perhaps even less severe disabilities. Cultural factors, such as differences in the degree of willingness to use or be seen using special equipment or to accept help from other people in lieu of technology, could also account for these differences. But it is important not to discount the very real possibility that these minority populations have less access to assistive technology. They may have less income with which to pay for AT out of pocket, lower participation in programs that offer AT or less access to AT when using such programs, or they may have less contact with healthcare providers, who are often people's primary source of information about assistive technology, as we will see in Chapter 5.

## Race and type of devices used

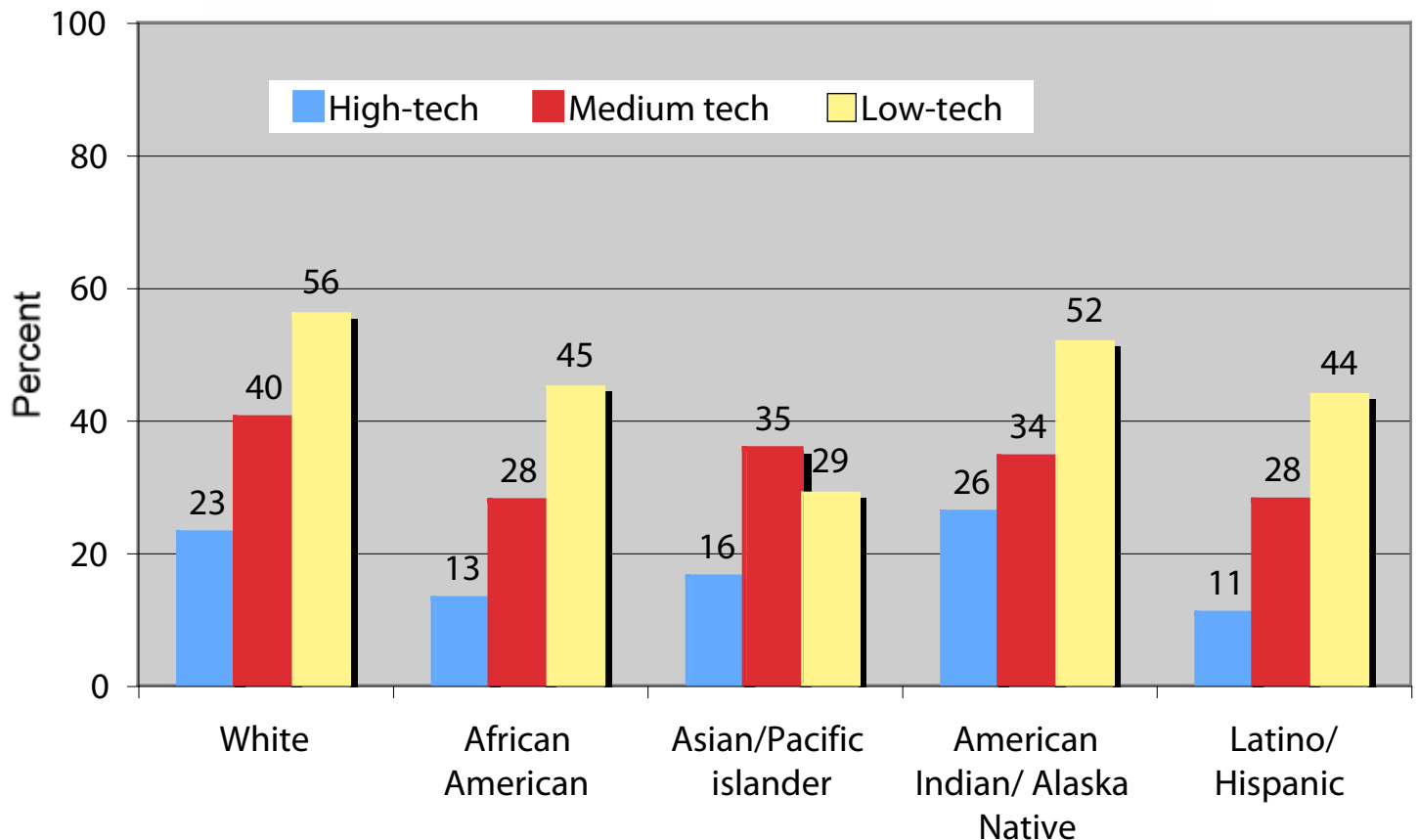
When we compare the types of technology people use, we find statistically significant differences among racial and ethnic groups for all three device categories. For high-tech equipment, in particular, usage is about twice as high among whites (23 percent use one or more high-tech AT devices) as it is among African Americans (13 percent) and Latinos (11 percent). A digital divide appears to separate these minority populations with disabilities from their non-minority counterparts with respect to their AT usage, similar in magnitude to the divide we saw between elderly and working-age respondents.

The gap in usage of medium tech devices is

also large, with 28 percent of both African Americans and Latinos using devices of this type, compared to 40 percent of whites. For low-tech devices, the gap is a bit less pronounced: 45 percent of African Americans and 44 percent of Latinos use low-tech devices, compared to 56 percent of whites.

Once again, small sample sizes for the Asian/Pacific Islander and Native American groups limit our ability to draw conclusions about their usage of specific devices. The only statistically significant comparison is that only 29 percent of Asians and Pacific Islanders in the sample use low-tech devices, compared to 56 percent of whites.

**Usage of high-, medium-, and low-tech assistive devices, by race/ethnicity**

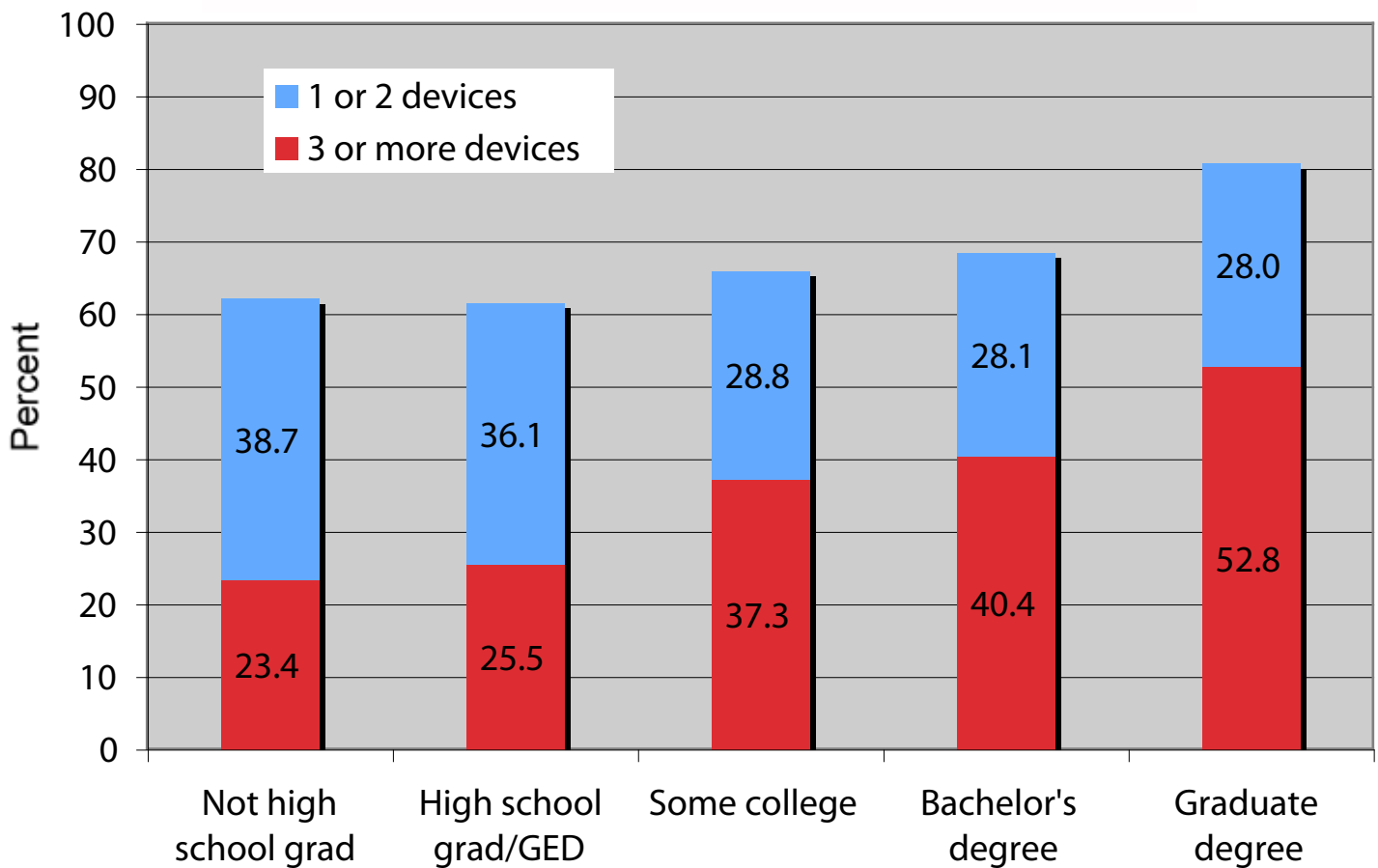


## How does AT usage vary by education?

AT usage increases markedly with a person's educational attainment. Although only about three-fifths of respondents with a high school education or less reported using any type of AT (62 percent of both those without high school diplomas and those with high school diplomas but no college attendance), about four-fifths of those with a graduate degree used AT (81 percent). Heavy usage of AT increases even more dramatically with education, with the proportion of respondents using 3 or more devices more than doubling from 23 percent for those without high school diplomas to 53 percent for those with graduate degrees.

Why do better educated respondents use so much more technology? We believe that the most important reason is that the more educated a person is the more likely he or she is to be aware of available technologies, and to have the wherewithal to investigate and keep abreast of relevant devices. Maybe education also makes a person more willing to experiment with unfamiliar technologies. There's also the fact that people with more education have a greater earnings potential, and can more easily afford costly equipment. But education seems to have a stronger influence on technology usage than does income, as we'll see later in this chapter.

**Extent of AT usage, by educational attainment**



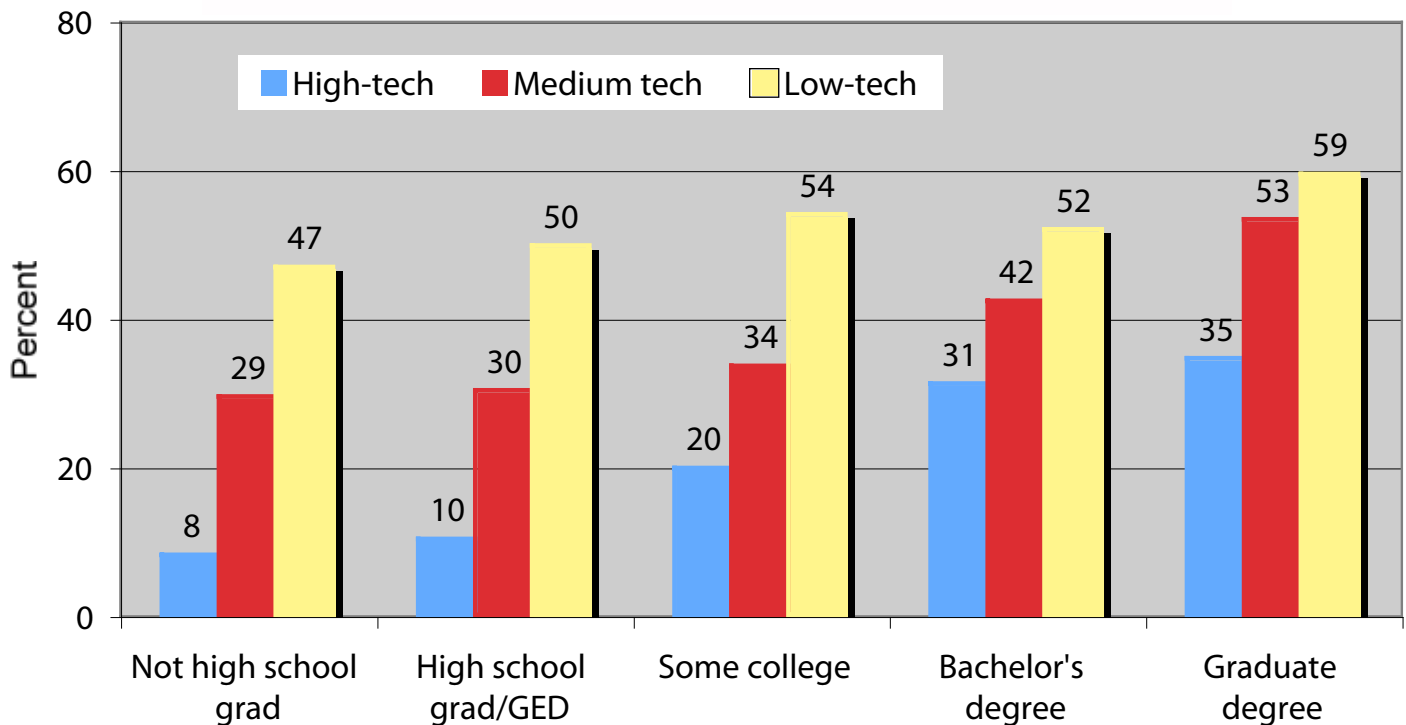
## Education and type of devices used

Usage of all types of AT increases with the amount of education a person has, but the most dramatic increase is for high-tech devices. People with a college education are about four times as likely to use a high-tech device as people without a high school diploma (35 percent for those with graduate degrees and 31 percent for those with bachelor's degrees compared to 8 percent for those without high school diplomas).

group compared to 29 percent for the least educated. Usage of low-tech devices increases with education from 47 percent to 59 percent of respondents.

Medium-tech device usage is also substantially higher for those with more education—53 percent for the most educated

**Usage of high-, medium-, and low-tech assistive devices, by educational attainment**

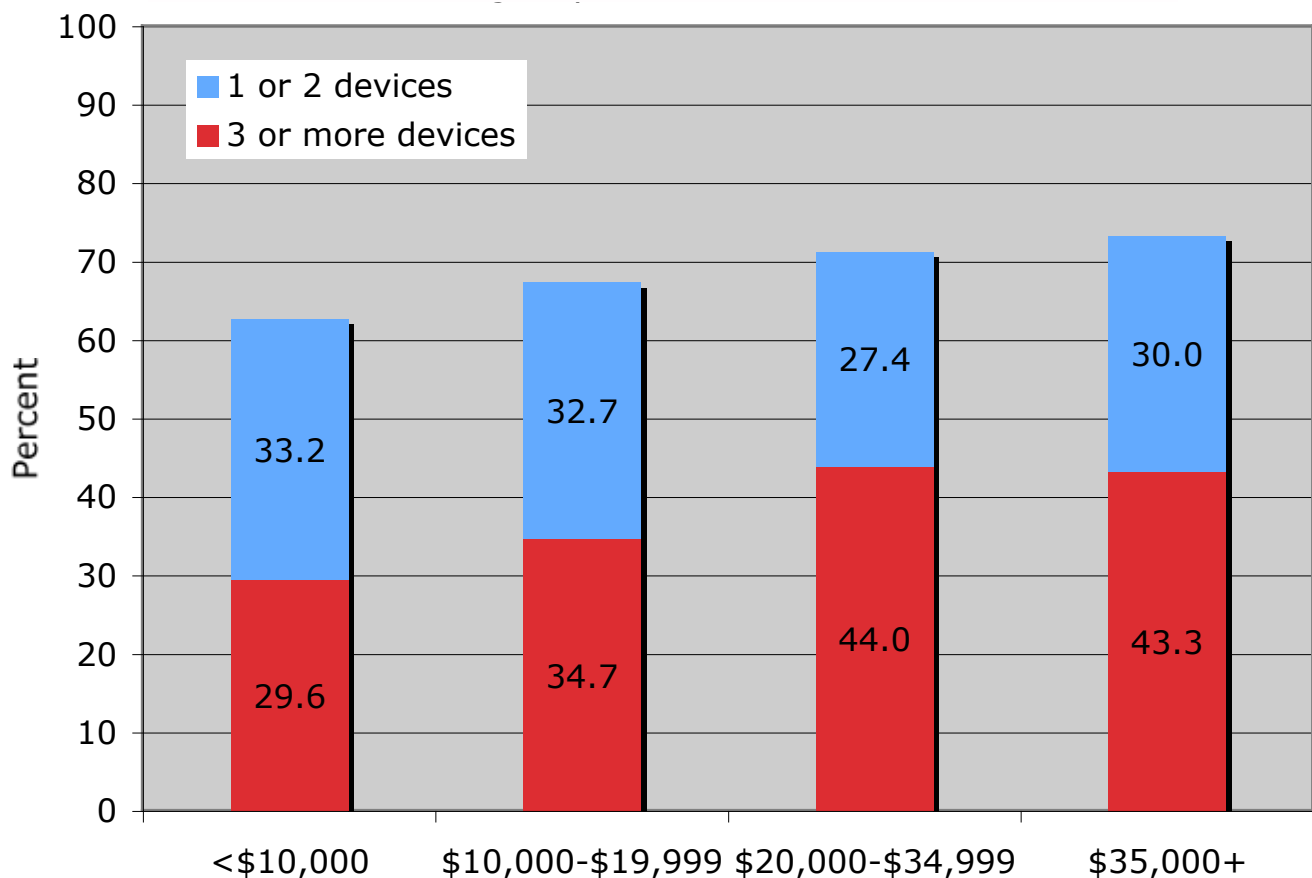




## How does AT usage vary by income?

Later we'll describe how Independent Living Center consumers acquire their assistive technology, whether they pay for it themselves or it is purchased for them. Because many people, especially those with fewer economic resources, are able to obtain devices from public programs, there is only a relatively modest relationship between income and overall AT usage. Among the least wealthy group of respondents in our sample (annual household income less than \$10,000), 63 percent used some form of assistive technology, compared to 73 percent of those with incomes of \$35,000 per year or above.

**Extent of AT usage, by annual household income**



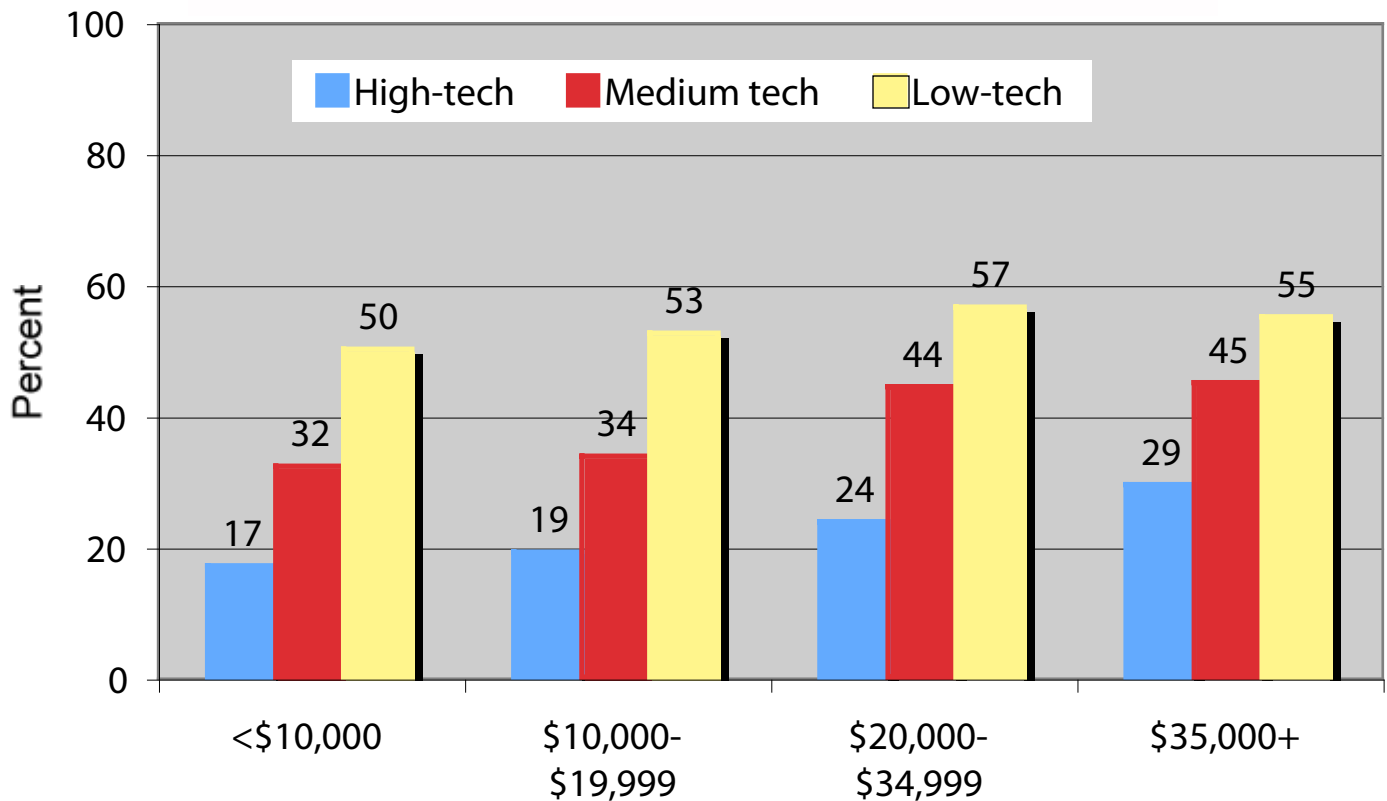
## Income and type of devices used

Usage of low-tech assistive devices—those that are neither electronic nor motorized—varies very little with household income. Many such devices are inexpensive or available to eligible consumers for free from public programs. Usage of more costly or sophisticated devices, however, does increase substantially as a household’s income increases and out-of-pocket purchase of such devices becomes more feasible.

those with the least household income to 29 percent among those with the most income, an indication of a fairly substantial digital divide in AT usage by income. Usage of medium-tech devices—a category that includes costly equipment like power wheelchairs and adapted vehicles—increases with household income from 32 percent to 45 percent. Only a small variation is seen in usage of low-tech devices, ranging from 50 to about 55 percent.

As shown in the chart, usage of high-tech devices increases from 17 percent among

**Usage of high-, medium-, and low-tech assistive devices, by annual household income**



## Income and type of mobility device used

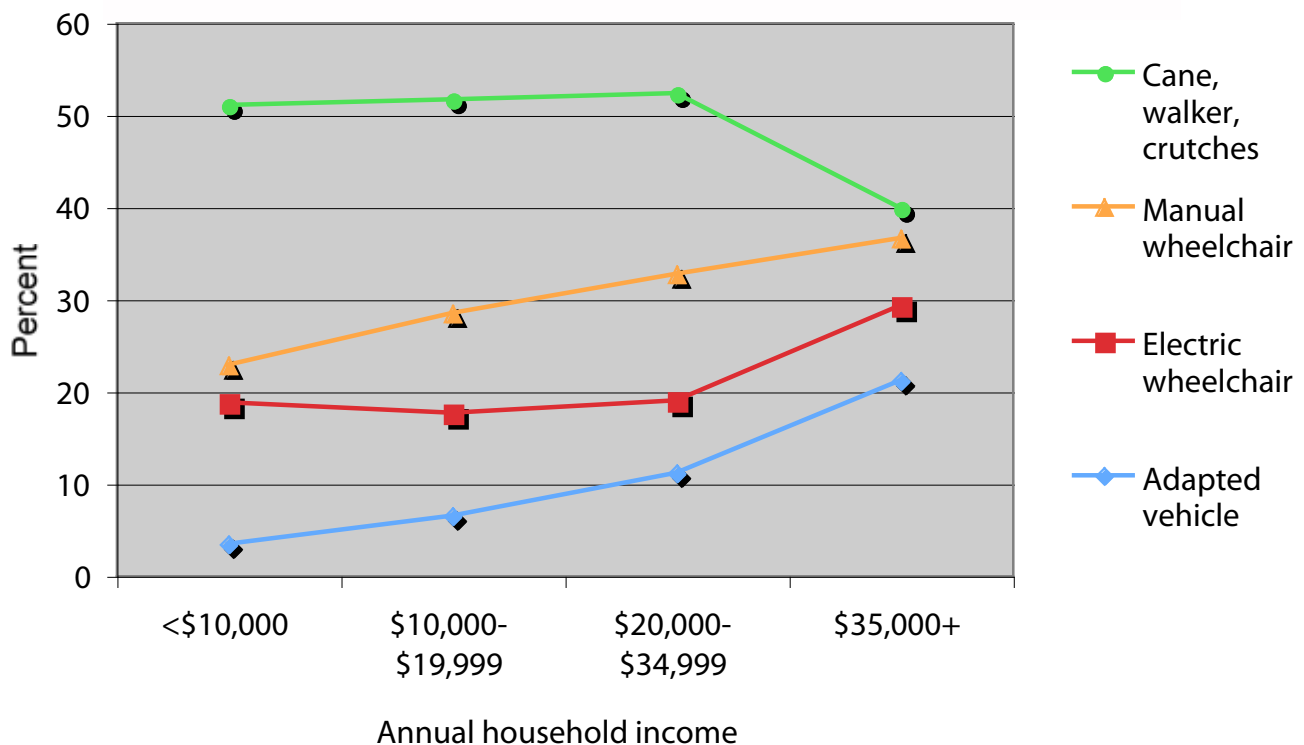
Mobility device users provide an illustration of the way in which usage of specific devices varies with household income. Among respondents with mobility impairments, usage of specific mobility technology is strongly affected by income, with the wealthiest group of respondents (whose annual household incomes of \$35,000 or more is relatively modest) more likely to use more sophisticated devices and less likely to be relegated to more primitive devices.

As the chart shows, usage of manual wheelchairs (median price of \$1,800 as reported by our sample) increases steadily with household income, from 23 percent for those with less than \$10,000 income to 37 percent for those with \$35,000 or more. Usage of electric wheelchairs (median cost \$8,000) remains just below 20 percent for all income

groups except the highest, for which it rises to 29 percent. But usage of canes, crutches, and walkers (median cost for this category of devices in our sample was \$25), which holds steady at just above 50 percent for the lower income groups, drops to only 40 percent for the highest income group, who could readily afford these devices if they needed them. This finding seems to imply that people who can afford to do so purchase more costly devices and use them instead of the more primitive devices that the poorer consumers must use instead.

Also shown is the rate of usage of adapted vehicles, usage of which increases six fold with income, from 3 percent of those in the lowest income category to 21 percent in the highest.

**Usage of mobility technology among respondents with mobility impairments, by income**



## Conclusions

Assistive technology devices are important fixtures in the lives of our Independent Living Center respondents, with two-thirds indicating they use at least one device to carry out daily living activities and about half indicating they used multiple devices. The fact that a majority of respondents have multiple disabilities (as reported in Chapter 2) means that often more than one device is needed to maintain the person's independence.

People with mobility, sensory, or speech impairments are more likely to use AT than other disability groups, and there is a wide variety of equipment and tools available to help with those functions. Accommodating people with these limitations has a long history; as a society we have seen and heard more about these types of equipment and the people who use them. Actor Christopher Reeve, physicist Stephen Hawking and returning veterans who have lost limbs have all demonstrated what is possible.

We find it disturbing that respondents who have cognitive or mental health disabilities were far less likely to use equipment to help cope with their functional limitations. As we will see in later chapters, they have far less information about equipment. When we look at respondents with just a cognitive disability, we find that only 22 percent use some sort of AT; those with only mental health disabilities use even less at 13 percent. Compare these figures with individuals who use AT and have a mobility disability (87 percent), a hearing disability (77.5 percent) or a visual impairment (70 percent) and the gap becomes quite obvious.

Why is this? Is it because no one is developing effective tools to support people with cognitive or mental health disabilities? Or those tools exist, but people don't know about them? We certainly don't have high-profile role models with these disabilities publicly blazing the trail, equipment in hand, so the general public's comfort level with this type of disability is less. Is it because the helping professions that most work with individuals with cognitive or mental health limitations either don't know about equipment or believe that their consumers can't or won't use the equipment? More research is needed in this area, as is more education for consumers, their families and care providers about what is out there and how to use it. Even just looking at existing tools and making sure that people with these types of limitations are offered them is an important activity. For example, an electric toothbrush that has a built-in timer to make sure that all parts of the mouth are covered is a terrific tool for good dental health, often a problem for people with cognitive impairments. We believe more attention on devices for these two populations is greatly needed.

When we look at age, we find that the rate of usage rises with age. That makes sense because as people age they tend to acquire more functional limitations. Their eyesight weakens, their hearing starts to diminish and they may not be able to walk as well, for example. People over the age of 85 are twice as likely (55 percent) to be heavy users of AT as adults under the age of 25 (28 percent). By heavy users we mean using 3 or more devices.

However, a funny thing happens when we look at the type of equipment people use according to their age. Low-tech devices are the basic simple things—manual, non-electronic devices. Medium-tech devices are those that are electronic or motorized, such as electric wheelchairs, scooters, hearing aids and adapted telephonic equipment. High-tech equipment includes those things that are digital, such as computers, adapted software, and speech synthesizers.

When we look at equipment in these groupings by the age of the users, it becomes apparent that the oldest respondents are much more likely to use low-tech devices than the youngest respondents and much less likely to use high-tech devices. Is this because seniors like simpler equipment, or are they not offered medium or high tech options? We predict that, as the Boomer generation ages, the demand for medium- and high-tech equipment will explode, at least for those who have money. A particularly disturbing finding from our study is that, among people with mobility impairments, those who are wealthier are much more likely to be using higher-tech devices, while the poorer respondents are forced to get by with mostly lower-tech devices.

More dramatic than income is the effect of education on AT usage. Highly educated respondents were more than twice as likely as poorly educated respondents to be heavy AT users, and more than four times as likely to use high-tech devices. Well educated people are generally more aware of available technologies, are more able to do their own research to find the devices they need, and they may also be more comfortable using

more sophisticated or higher-tech devices. The importance of increasing awareness of available technologies, and of clearly demonstrating their benefits to those unfamiliar with them, cannot be overstated.

In terms of disability onset, the heaviest users of AT (in other words, the groups with the highest proportion using three or more devices) are those who were either born with a disability or acquired it late in life. Individuals who were born with their disability likely were introduced to AT through early childhood programs and schools that must consider AT when writing an individualized education program. While meager, there is some AT funding available for children. Likewise, seniors just acquiring disabilities have access to Medicare and may have funds accumulated through a lifetime of work. Those acquiring disabilities in later childhood or early or middle adulthood may have fewer financial resources and fewer support systems to help them find and acquire the tools they need to accomplish daily life activities.

Turning our attention to the how AT usage varies by race/ethnicity, we find significant gaps. African-Americans and Latinos were less likely to use any AT than their non-minority counterparts. Particularly dramatic gaps are present in usage of multiple devices, and in usage of high-tech devices.

The gaps in AT usage by race/ethnicity could be explained by other demographic factors, such as lower average age or educational attainment. As we will see in a later chapter, access to sources of information about AT plays a role in this finding. Cultural

factors are very important to consider, because members of some cultures may not value independence as much or may not wish to be seen using special equipment. However, there is a very real possibility that minority groups have less access to devices, for a number of reasons that need to be addressed as we reach out to these groups and present information in a culturally sensitive manner. Regardless of cultural background, every person with a disability needs information about and access to relevant assistive technologies so that they can make their own decisions about what tools they need to live as independently as they wish.

Groups with lower levels of AT usage include people with cognitive or mental health disabilities, people who are African-American or Latino, younger adults, and people with less education or income. In terms of types of equipment, older adults, African Americans, Latinos, and people with less education or income are less likely to use more sophisticated equipment. Gaps in AT usage can arise from lack of funding to purchase equipment or from attitudes toward disability or using devices held by the individual, the family, or the service provider. Targeting education and funding dollars for AT toward these gaps will help close them.

## Chapter 4

# Unmet Needs: Barriers to AT

When individuals don't have the tools they need to live, learn, work and play as independently as possible, their lives are greatly diminished. Not having a functional wheelchair means someone may not get out of bed. Not having adapted eating utensils means depending on a human assistant to get nourishment. Not having a hearing aid or access to the telephone relay system for the deaf can interfere greatly with communication and even safety. Sometimes, not having the right equipment can lead to institutionalization, a fate dreaded by consumers and costly to society. These scenarios illustrate the significant barriers that people can face without the appropriate tools to function fully and contribute to their community. Isolation, depression and greatly reduced self esteem, as well as a lack of commitment to life goals, can result. **Reasons for unmet need focus on lack of funding and/or lack of knowledge as to what equipment is out there and how to get it.**

In this chapter we will present data on those barriers, explore the unmet need for equipment, and show how equipment that is acquired is located and paid for. Finally we will report on problems with equipment and how our respondents think the "system" for getting AT should be changed for the better. Then, in Chapter 5, we'll highlight the benefits that AT users get from their technology.

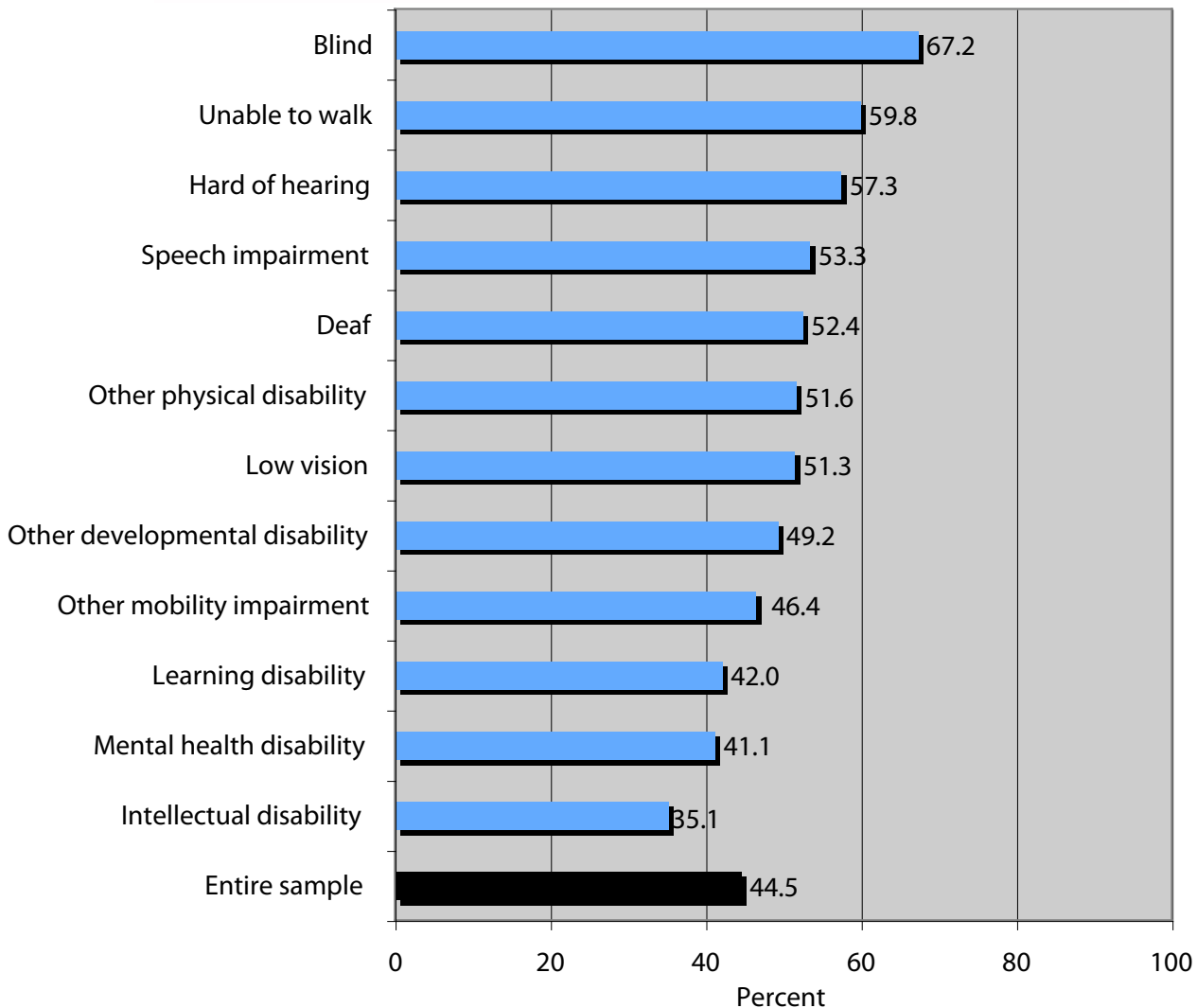
It is important to note at the outset that this chapter is based entirely on respondents' own expressions of unmet need for AT, and therefore it probably understates the true unmet need. People can only express a need for technology that they know about and believe can help them. However, lack of information is a top barrier. We know that many individuals may not know what they don't know. In other words, they may not know about all the equipment or the latest equipment that can assist them. Still, the results that follow give us plenty of direction for change.

## Unmet need

When respondents were asked if there were any AT devices that they needed but did not have, a whopping 45 percent of the entire sample responded that they did have an unmet need. Examining the extent of unmet need by disability indicated that persons with sensory or speech impairments, or who were unable to walk or had other physical disabilities, had the highest unmet need, ranging from 51 percent to 67 percent. Surprisingly, those who experience cognitive or mental health disabilities expressed less unmet need for equipment. Because

these groups are also the lowest users of technology in our sample, we suspect that people with these types of disabilities don't know about equipment that might assist them. Perhaps service providers working with these individuals either don't know about the equipment themselves or assume that the consumer would be unwilling to use equipment and don't offer it. Alternatively, the consumers or their service providers may know about available technology, but do not regard it as worthwhile. This is an area that needs further research.

**Expressed unmet need for AT, by disability type**





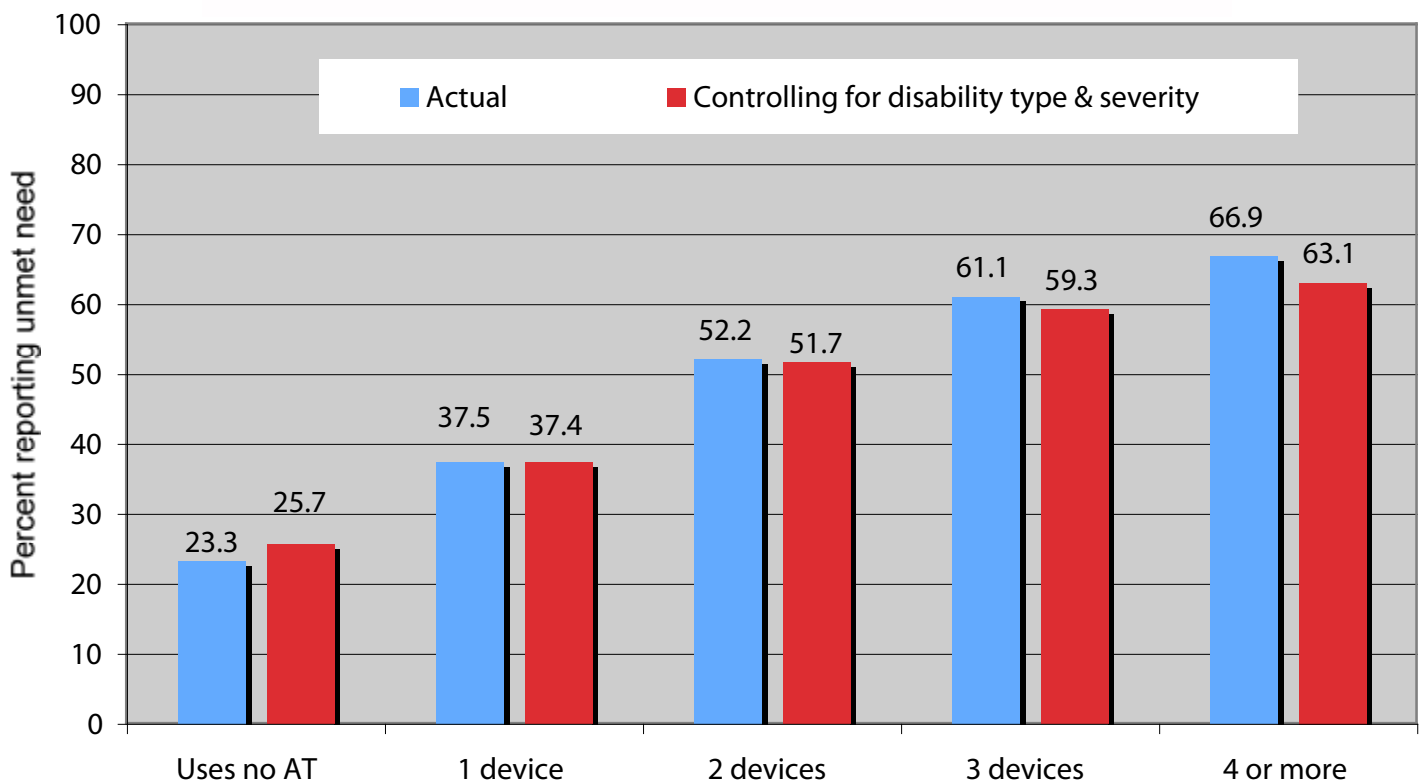
## Unmet need by extent of device usage

We wondered about the relationship between how much AT people used and whether or not they expressed an unmet need for AT. Is unmet need highest among people who don't use any AT, and lowest among people who use a lot of AT? On the contrary, to our surprise, people who are heavy users of AT are much more likely to say that they have an unmet need for AT than people who don't use any AT at all. The chart below shows the level of unmet need as reported by the respondents, increasing steadily from 23 percent for non-users of AT all the way to 67 percent for the heaviest users of AT (4 or more devices per person). We suspect that people who use a lot of AT are highly knowledgeable about the kinds of technologies that can help them, and therefore are more likely than non-users to

be aware of AT that is available, but they are unable to obtain.

Another possibility is that those who use the most equipment have more severe disabilities, and that they both use a lot of AT and have more unmet need for AT as a consequence. To test this possibility, we constructed a statistical model in which we controlled for the type and severity of disability; in other words, we adjusted the data as if everyone in the sample had a similar level and type of disability. We found that even after controlling for severity, the unmet need is still higher as one uses more equipment. It is apparent that the more one uses equipment, the more aware one is of other pieces that could be helpful.

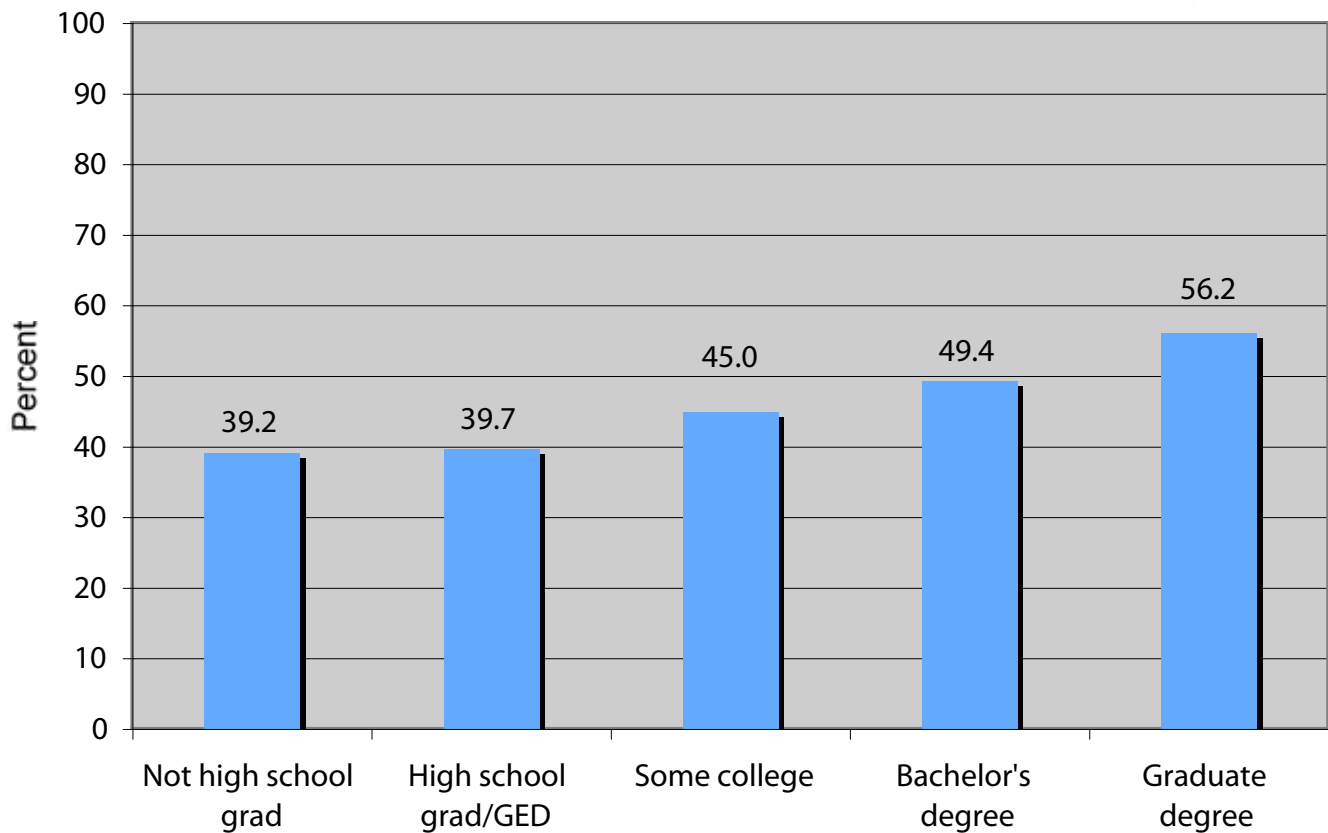
**Expressed unmet need for AT, by number of devices used**



## Unmet need and educational attainment

The next chart shows how unmet need increases with educational attainment. Substantial unmet needs were reported by all levels, starting with nearly 40 percent of those with a high school diploma or less and rising to 56 percent for those who hold a graduate degree. Clearly the more education one has the more he/she is aware that there is additional equipment out there that can help. But even those without a lot of education knew there was equipment available that they could use.

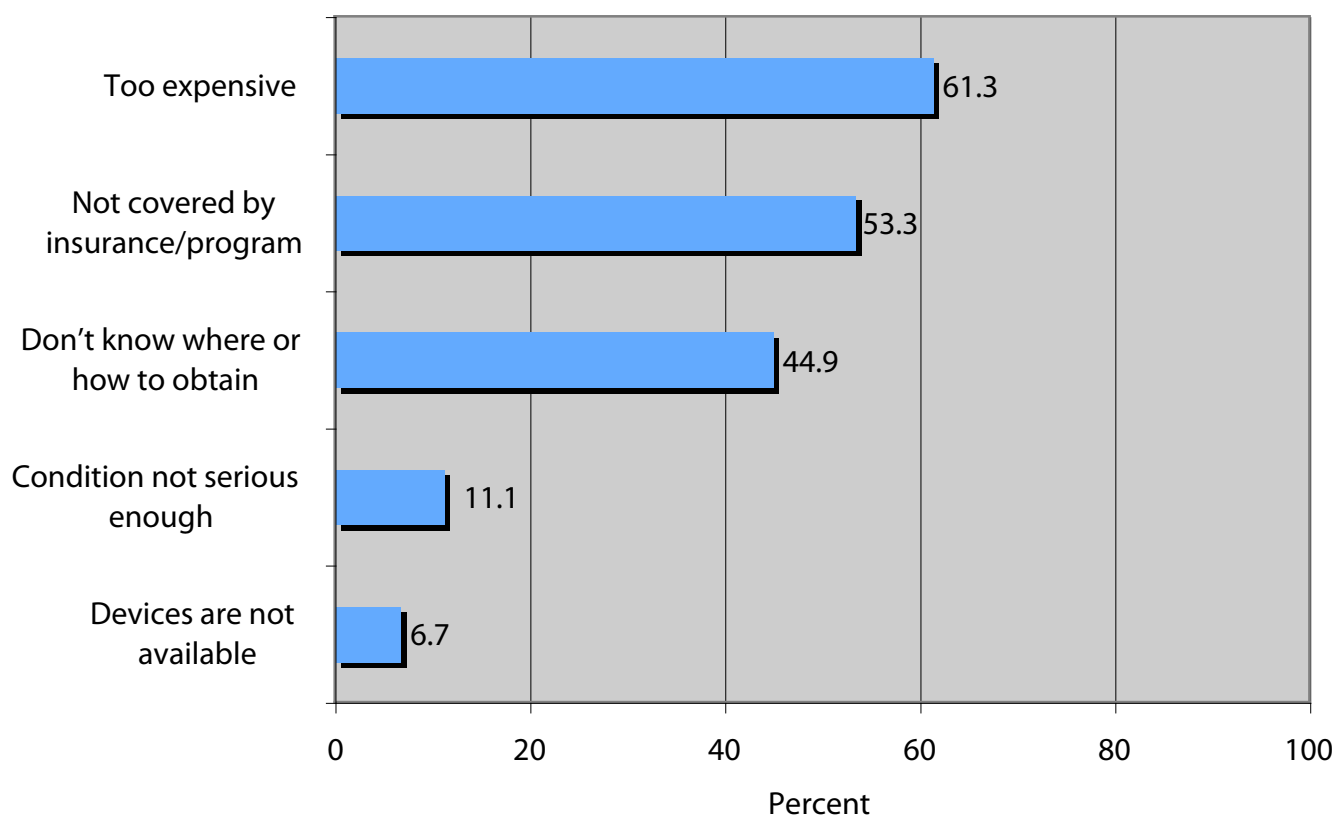
**Expressed unmet need for AT, by educational attainment**



## Reasons for not having AT

Respondents cited three primary reasons for not having the equipment they felt they needed. Two are related to the respondent's inability to pay for the devices out of pocket: "too expensive" (61 percent of respondents with unmet need) and "not covered by Insurance/Medi-Cal/Medicare" (53 percent). The third was lack of knowledge as to where or how to obtain the devices (45 percent). Only a small percentage stated that their disability wasn't serious enough and a few said the equipment they needed wasn't available.

**Reasons for not having needed AT, among respondents expressing unmet need**



## What equipment do people need?

After looking at the unmet need for equipment and the reasons people don't get what they need, we wondered what sort of equipment people wanted that they did not have. The top items respondents mentioned are listed below with a range of costs for each one.

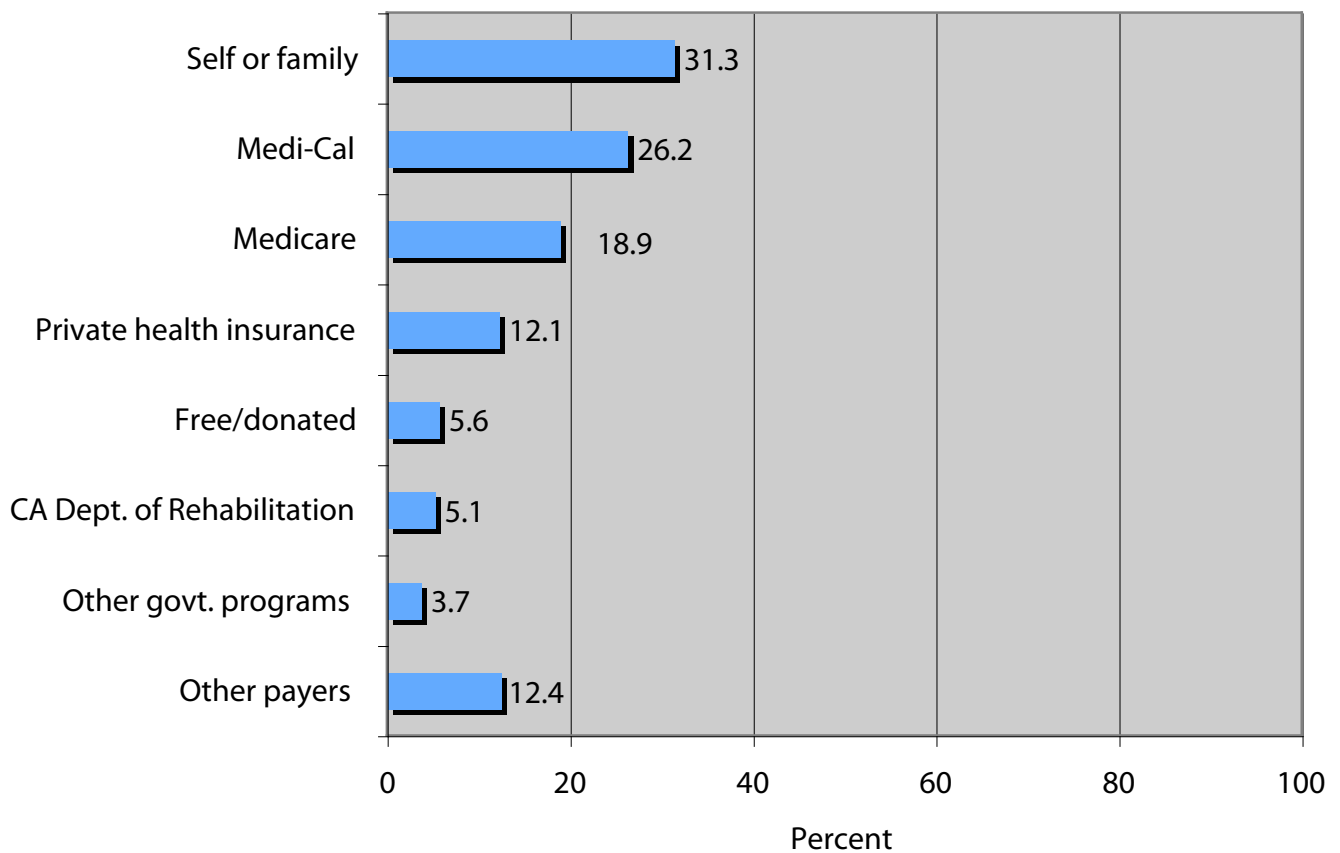
Taken on an individual basis, the costs vary from inexpensive to quite costly. For the mostly low-income consumers of Independent Living Centers in our sample, having to purchase the more costly equipment on their own could pose an insurmountable barrier, as could having to buy several of the less expensive devices.

<b>Top devices and technologies for which respondents express unmet need, and typical cost of the device or technology</b>		
	<b>Device or technology</b>	<b>Typical cost</b>
1	Electric wheelchair or scooter	\$1,000–\$30,000
2	Adapted computer or special hardware or software	\$50–\$6,000
3	Ordinary desktop or laptop computer or PDA	\$300–\$5,000
4	Adapted or ordinary vehicle, or vehicle modifications	\$300–\$52,000
5	Home modifications for accessibility	\$20–\$15,000
6	Hearing aid	\$500–\$7,500
7	Adapted phone, cell phone, or answering machine	\$0–\$1,000
8	Grabber, reacher, kitchen utensils or devices	\$10–\$500
9	Other visual technology, e.g., magnifiers or CCTV	\$10–\$6,000
10	Other mobility device, e.g., cane or walker	\$15–\$800

## The barrier of money

When asked who paid for the equipment they use, respondents said that “self or family” was the top purchaser of equipment at 31 percent of devices. Given the very low annual income of the respondents, this finding was eye-opening. Medi-Cal (California’s Medicaid program) was the next source of payment (26 percent). Medicare was also an important payer (19 percent), but private insurance plans were a distant fourth (12 percent). Surprisingly, California’s Department of Rehabilitation was mentioned as a payer for only 5 percent of the equipment.

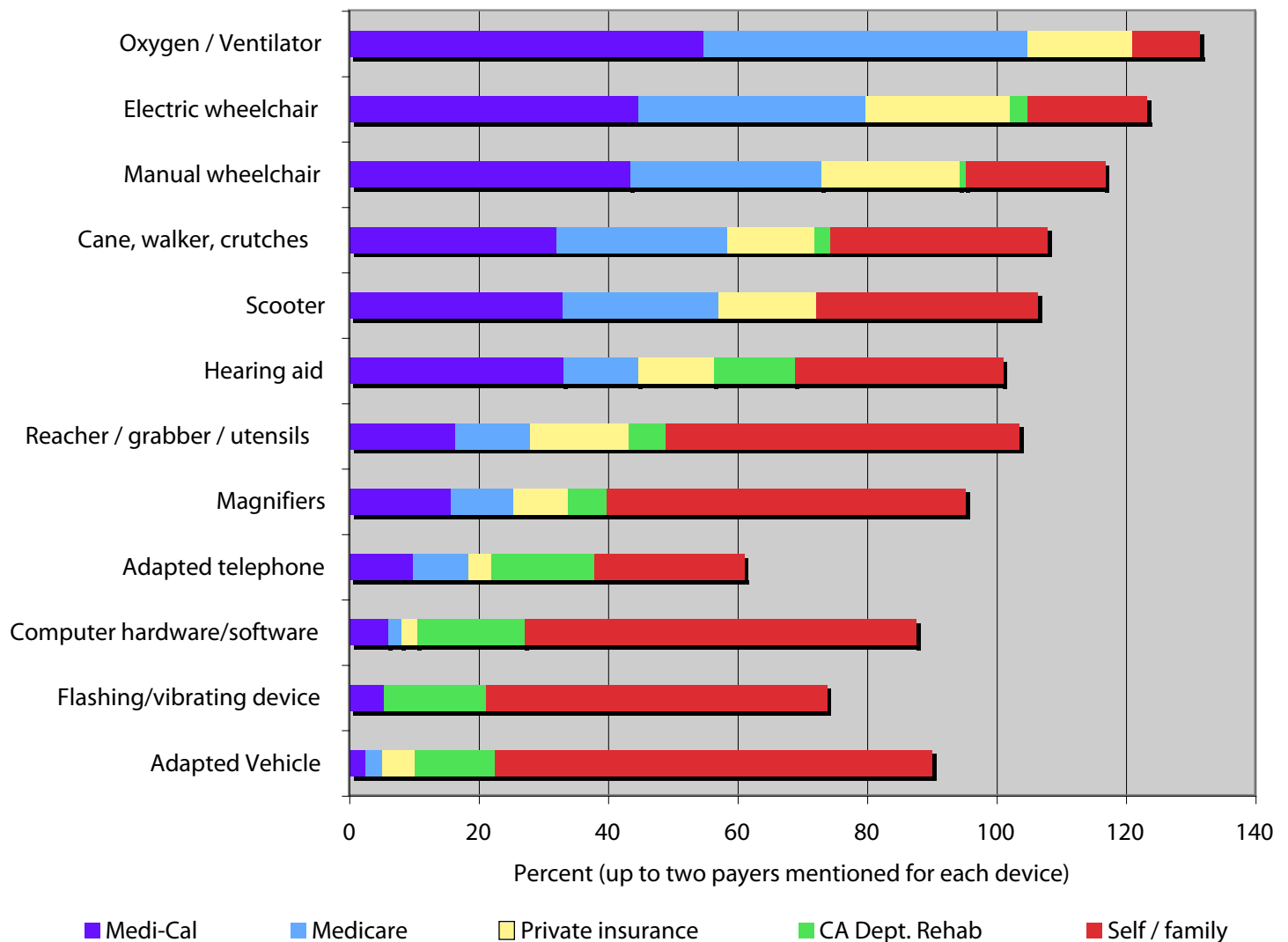
**Sources of payment for AT devices**



## Funding for specific devices

Looking at who pays for each type of device shows us which payers are more likely to pay for which kinds of devices. The “medically necessary” devices or “equipment for survival” (i.e., oxygen, mobility devices and hearing aids) are generally paid for by Medi-Cal, Medicare or private insurers. The Department of Rehabilitation generally focuses on work-related equipment, and consumers, including their families, often purchase the equipment critical to living independently and functioning in the community.

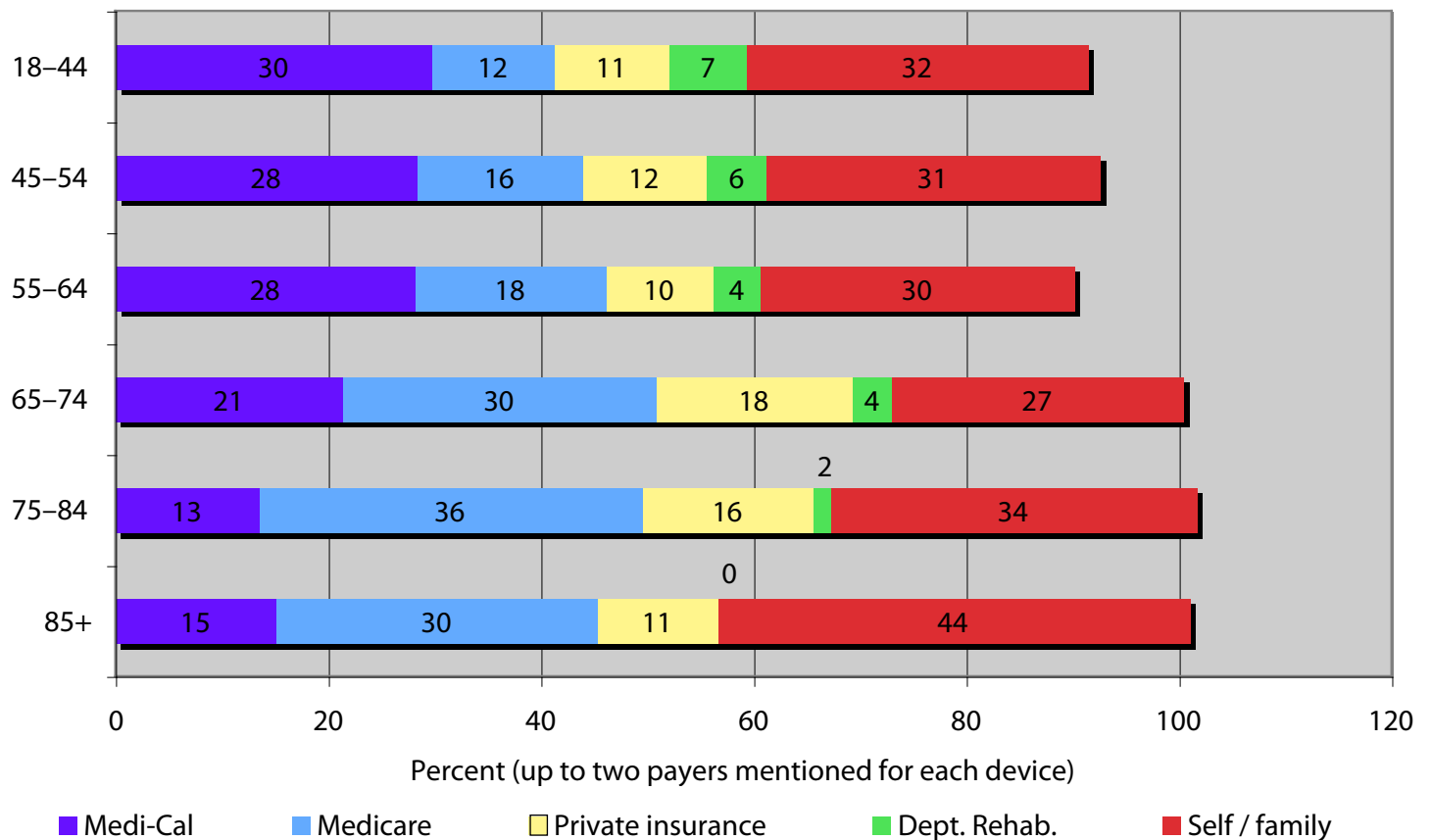
**Selected sources of payment for common AT devices**



## Funding by age

We wondered if there was a difference in who paid for equipment depending on the age of the consumer. Not surprisingly, the proportion of devices paid for by Medi-Cal goes down with age while the proportion paid for Medicare goes up. Younger adults with disabilities often rely on Medi-Cal while older adults are often covered under Medicare. Those on Medicare may be using their own funds partly because of the co-pay required by Medicare. However, this chart also presents clear evidence that consumers at any age are using their own funds at a significant level.

**Selected sources of payment for AT devices, by age**

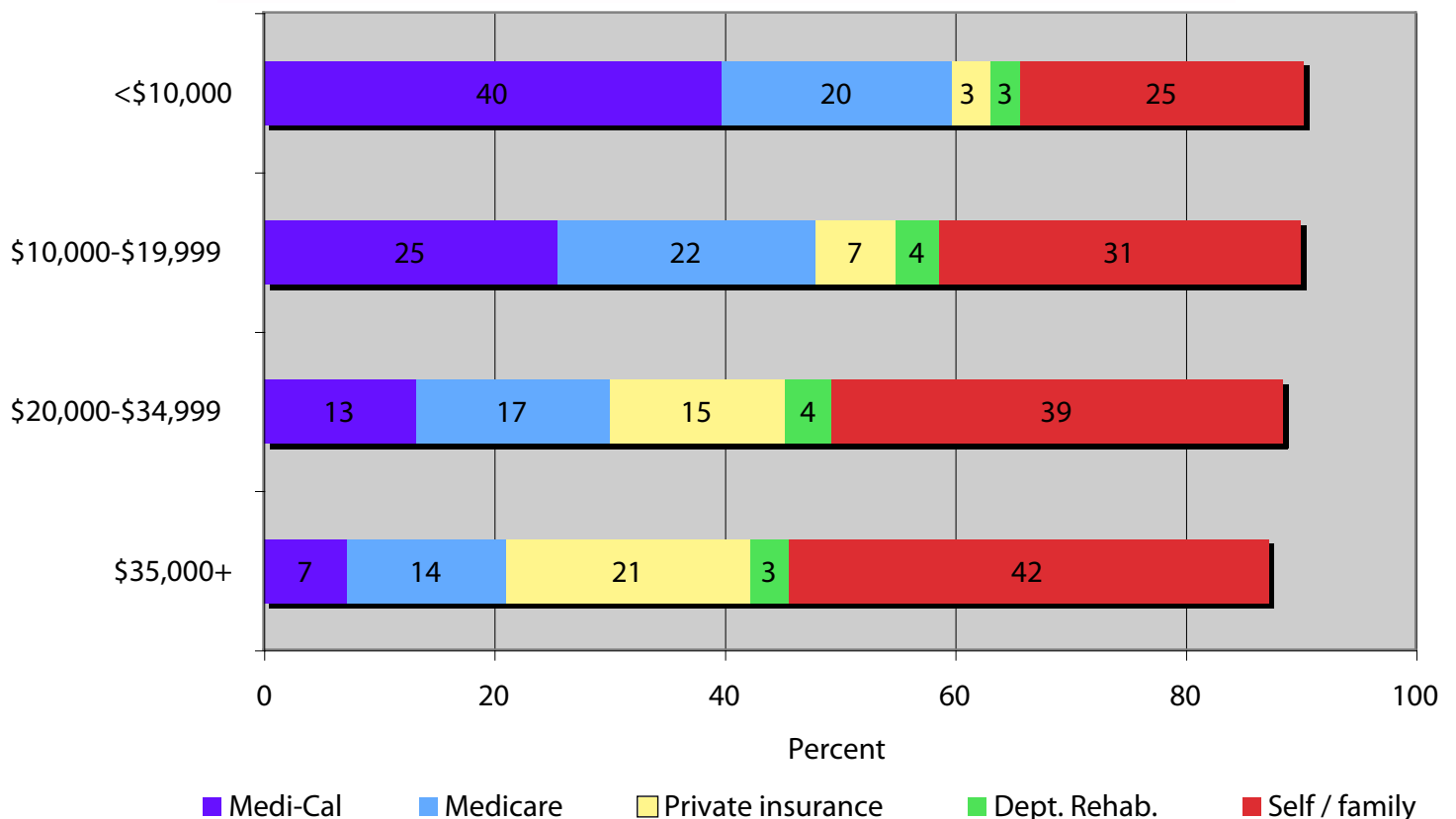


## Funding by income level

It is not surprising to see that, as people's income increases, they are less likely to rely on Medi-Cal. As income rises, consumers rely more on private insurance (presumably because they are working or have spouses who are working) and self pay.

But here again is evidence that there is strong consumer participation in purchasing equipment, regardless of income bracket. However given the low median income of this population (\$10,000-\$15,000), the fact that people at all levels make room in their budgets to purchase needed equipment underscores the importance of AT in their lives.

**Principal sources of payment for AT devices, by income**





## The information barrier

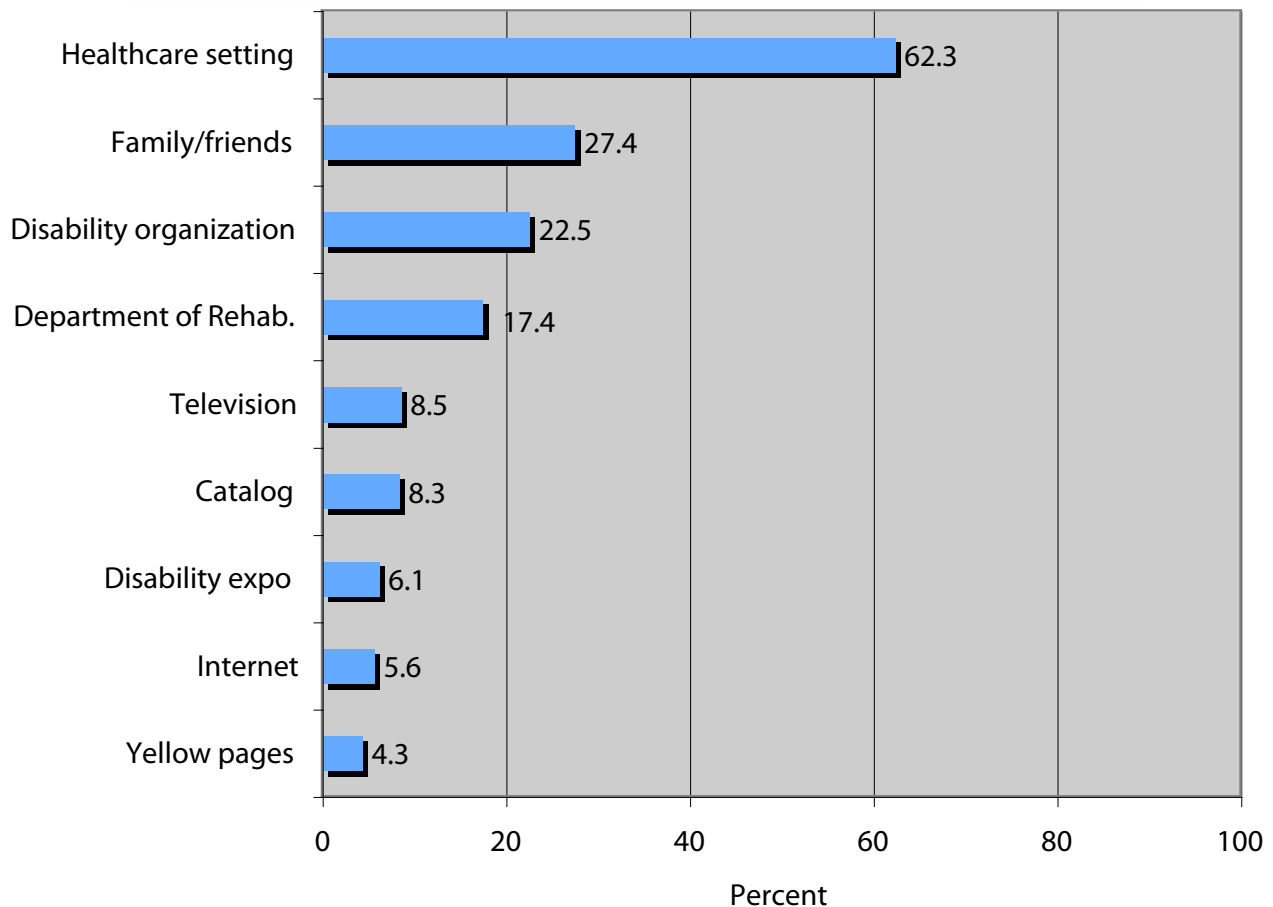
The other major barrier cited by respondents was finding out about equipment that could help them. When the survey was designed, there were some concerns about this line of questioning. If people don't know about equipment, how will they know what they are missing? So the questions focused on how consumers got their information and how they rated those sources of information. Many respondents listed multiple sources of information, so percentages add up to more than 100 percent.

Healthcare providers were cited as the most likely source of information, by 62

percent of our AT-using respondents. Family and friends were the second source, at 27 percent, and Disability organizations (including Independent Living Centers and the AT Network) came in third, at 23 percent. Other sources included TV, catalogs and the Yellow Pages.

The lack of information about AT has long been a barrier nationally; federally funded AT State Grant programs are mandated to help address this problem. In California, the AT Network, while under the operation of the California Foundation for Independent Living Centers, worked to put more information

**Sources of AT information**



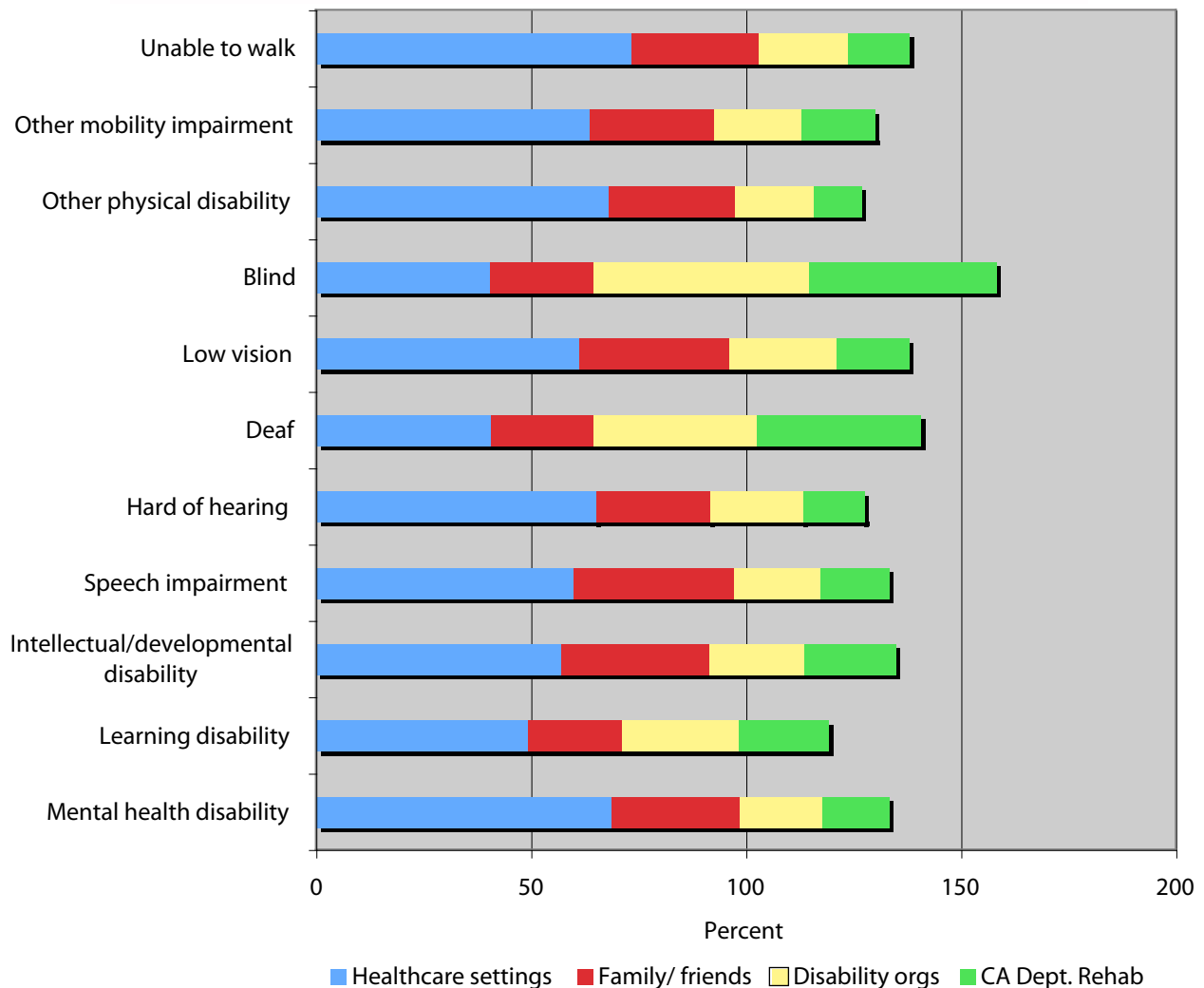
out through the local Independent Living Centers, an online “zine,” *The AT Journal*, appearances at community activities and shows, and press stories, as well as a website devoted to AT. Bus and radio ads were also deployed. The bus ads proved to be one of the most effective methods of outreach. People would call the toll-free number while riding the bus to inquire about the AT in the picture. Clearly, more work needs to be done, again and again, to educate people about the types of equipment out there and how to get them.

## Information sources for different disability groups

Looking at how people with different disabilities learned about the technology they use shows that some groups are less reliant on healthcare providers as sources of AT information. It is interesting to note that persons who are deaf or blind are less likely to learn about their AT devices from their healthcare providers than are those who are hearing impaired or have low vision. Has the medical profession given up on those who have lost most or all of either sensory ability? Or are they aware mostly of devices that can help people hear or see better, rather than technologies that enable people with more

severe impairments to participate in society without those abilities? Those who are blind or deaf indicate they are more likely to get information from disability organizations and the Department of Rehabilitation. Those with learning disabilities are also less likely than other groups to get AT information from healthcare professionals. This information gives us direction when considering where to expand the information about AT as well as to broaden the scope to include both medically necessary equipment and devices that foster community participation.

**Sources of AT information, by type of disability**



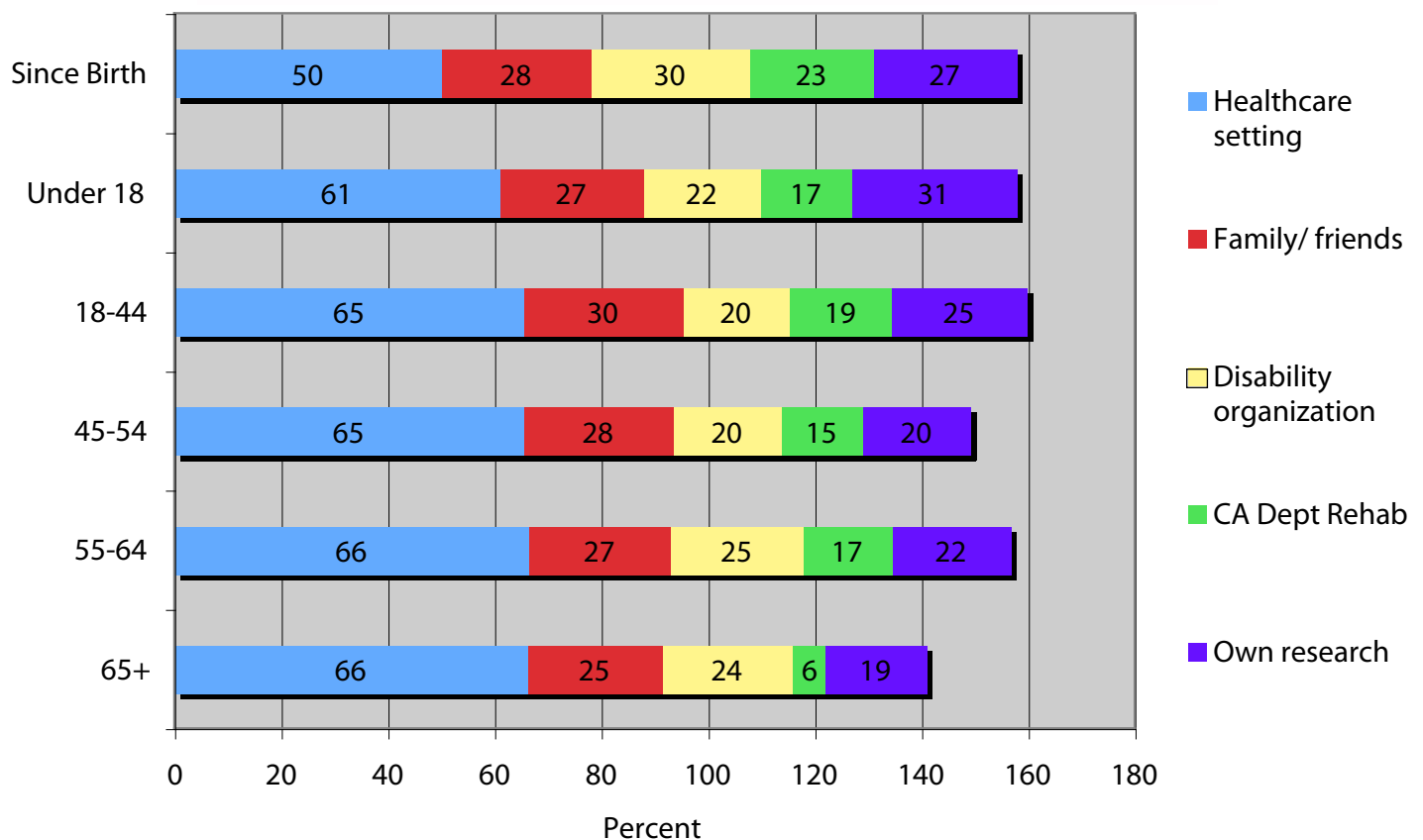
## Information sources by age of onset of disability

We looked at where people got their AT information according to when they first acquired their disability. While the chart shows that everyone primarily gets their information from their healthcare provider, people who have had their disability since birth or childhood are less likely to learn about AT from their healthcare provider than those with later onset. One reason for this could be because they are likely to have tried out equipment in school or through non-profit organizations who serve children with disabilities. People with birth-onset disabilities are especially likely to use alternative sources of information, such as disability organizations and the Department of Rehabilitation. Those whose disability

occurred prior to age 44 are more likely to get information from their own research than those acquiring their disability later in life.

People with elderly onset of disabilities are less likely to get information from the Department of Rehabilitation, which is consistent with their mission to serve people wanting to go to work. However, there is limited investment in keeping older working-age adults who acquire disabilities in the workplace. The policy seems to be to let them retire. This needs to be looked at as a gap in services for older workers. With proper equipment and job restructuring older workers can continue to be productive.

**Sources of AT information, by age of disability onset**

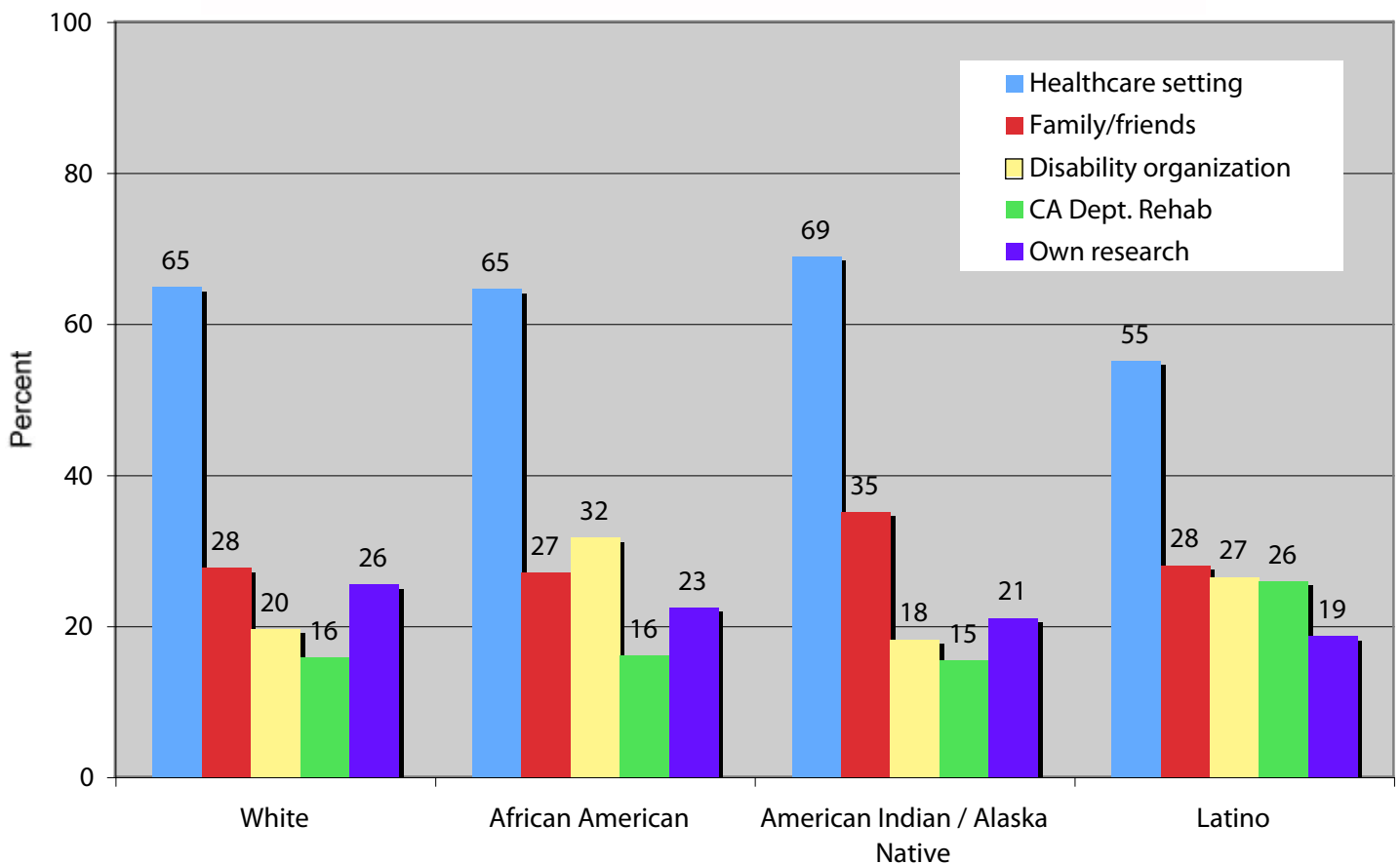


## Information sources by race

When we looked at sources of AT information by racial and ethnic groups, it becomes clear that Latinos are less likely than non-Hispanics to get their information from healthcare providers. Data from the 2001 California Health Interview Survey shows that among Californians with disabilities, Latinos were twice as likely as non-Latinos to NOT have seen a doctor in the prior year (15 versus 7 percent).

This tells us we need to find better ways of communicating with the individual with a disability and their families in racial/ethnic minority communities. Healthcare providers of Latinos need to make sure they are communicating about AT, at least as much as they do for other groups, regardless of immigration status. In addition, we need to use communication channels within each community and in the appropriate languages.

**AT information sources, by race**



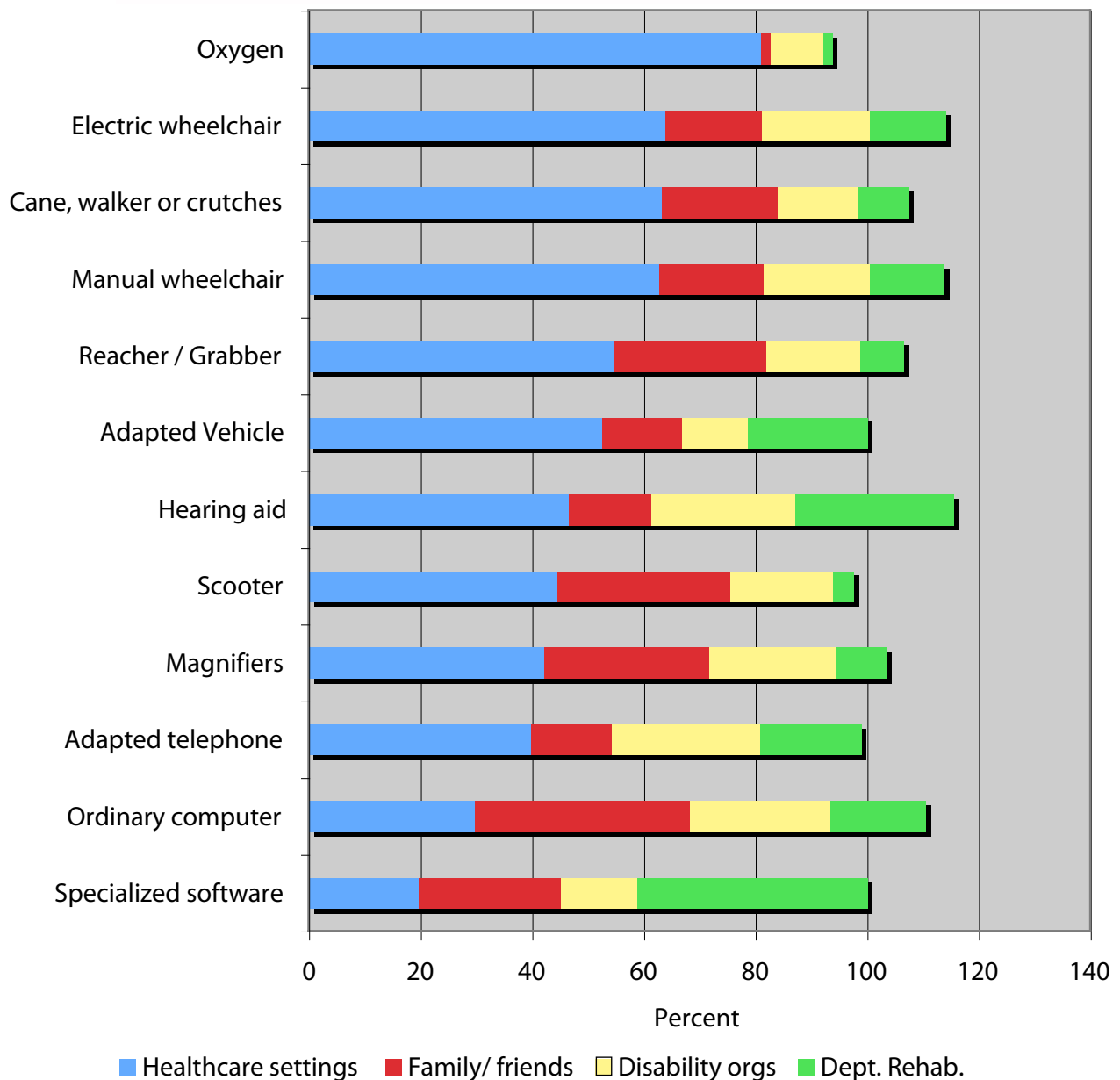
## Information sources by type of device used

Finally, when we looked at the information sources for common AT devices, we found that people were most likely to learn about “medically necessary” equipment from healthcare providers. Oxygen, electric wheelchairs, canes, walkers or crutches are all traditional medically-based equipment. But equipment such as computers and adapted phones

were more likely to be discovered through disability organizations and the Department of Rehabilitation. The problem with this situation is that many, many people with disabilities may never have contact with either of these sources of information.

In this day and age, people with even severe disabilities are living longer lives with an

**Information sources for common AT devices**



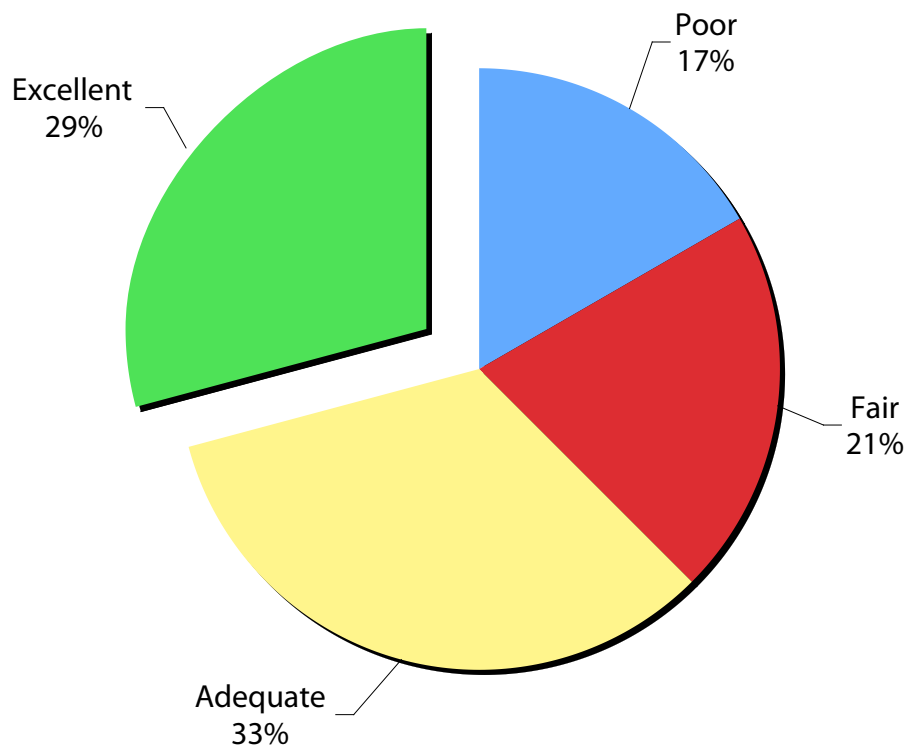
expectation of a higher quality of life; that is, they expect to participate in community life by having families, working, shopping and shaping their community's life. With the right equipment that expectation is achievable, but we must find a way to increase their access to information about those essential devices.

If the healthcare profession is going to be the principal source of AT information, then it needs to also be able to talk about telecommunications devices for the deaf, computer access, home modifications—the equipment that makes independence and community participation possible. Those are the factors that make up quality of life once the medical issue has been stabilized. If the healthcare community is not willing to take this on, then the disability-related organizations must increase their knowledge and step up the pace of disseminating information. Likely, both strategies will need to occur.

## How knowledgeable are healthcare providers?

Anticipating that respondents might name their healthcare provider as a significant source of information, we asked, "In your opinion, how knowledgeable is your primary health professional about the range of assistive technology?" Only 29 percent indicated that their healthcare professional's knowledge was excellent and 38 percent rated that knowledge as fair or poor.

**Primary healthcare provider's knowledge of AT**

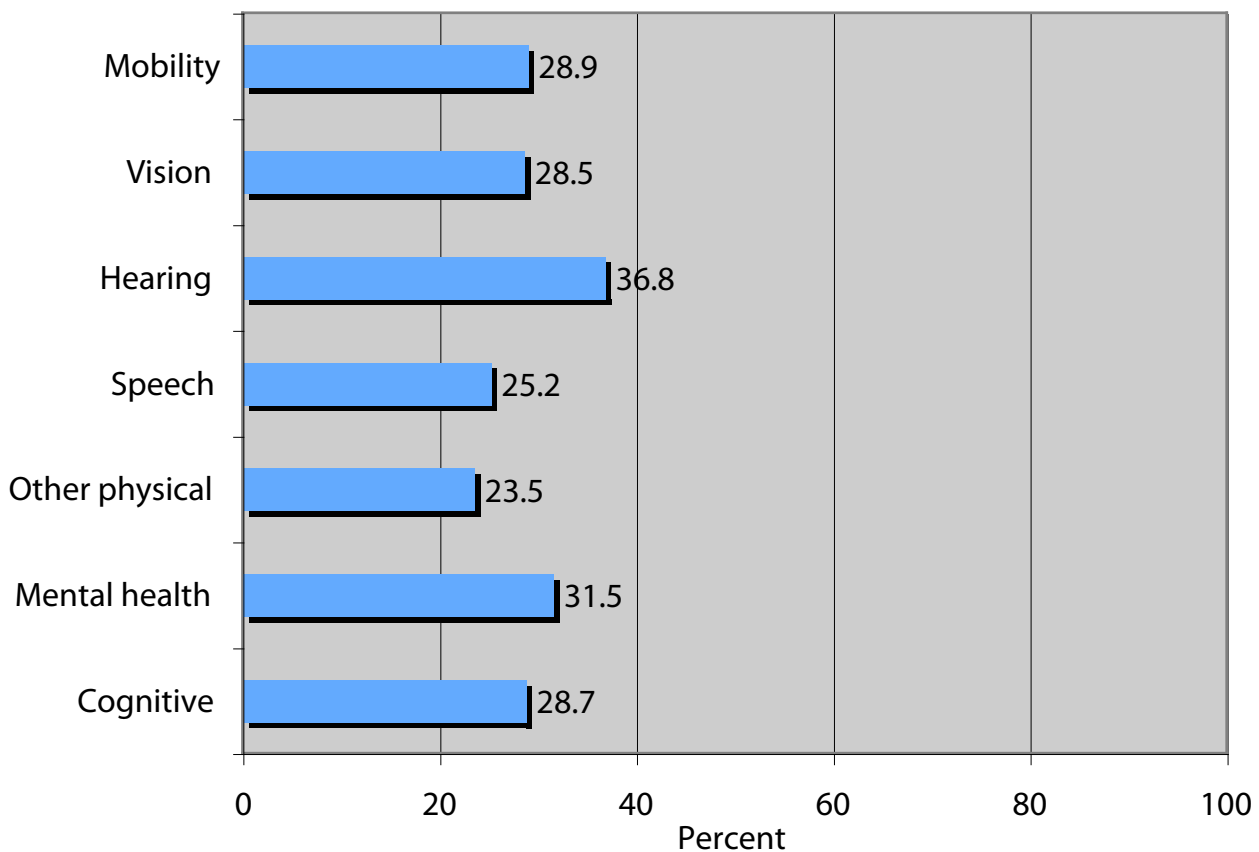




## Rating provider knowledge among different disability groups

Looking at the responses by types of disability (that is, asking if there is there a difference in the quality of information received by people with specific disabilities) it seems that no group is thrilled with their providers' knowledge. The groups with the highest regard for their practitioner's knowledge of AT were those with hearing impairments (37 percent rating their provider's knowledge of AT as "excellent") and those with mental health disabilities (32 percent). Individuals with other physical disabilities were least satisfied.

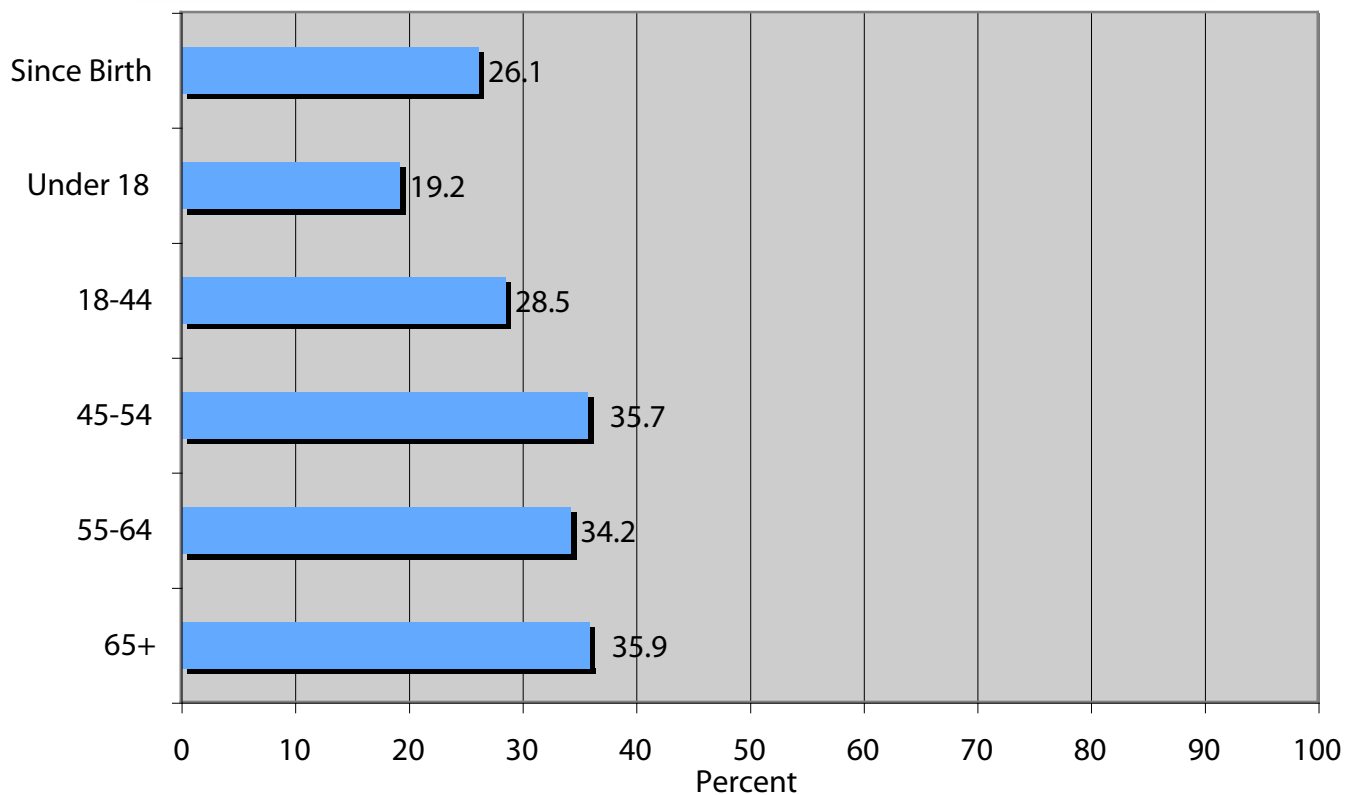
**Proportion rating healthcare provider's knowledge of AT as excellent, by disability type**



## Rating provider knowledge by age of onset

While a relatively small proportion of our respondents rated their health providers' knowledge of AT as excellent, people who acquired their disability later in life were more likely to do so. Roughly a third of respondents aged 45 and up rated their providers' knowledge as excellent while a quarter or less of those who have birth or childhood onset rated their healthcare providers similarly.

**Proportion rating healthcare provider's knowledge of AT as excellent, by age of disability onset**



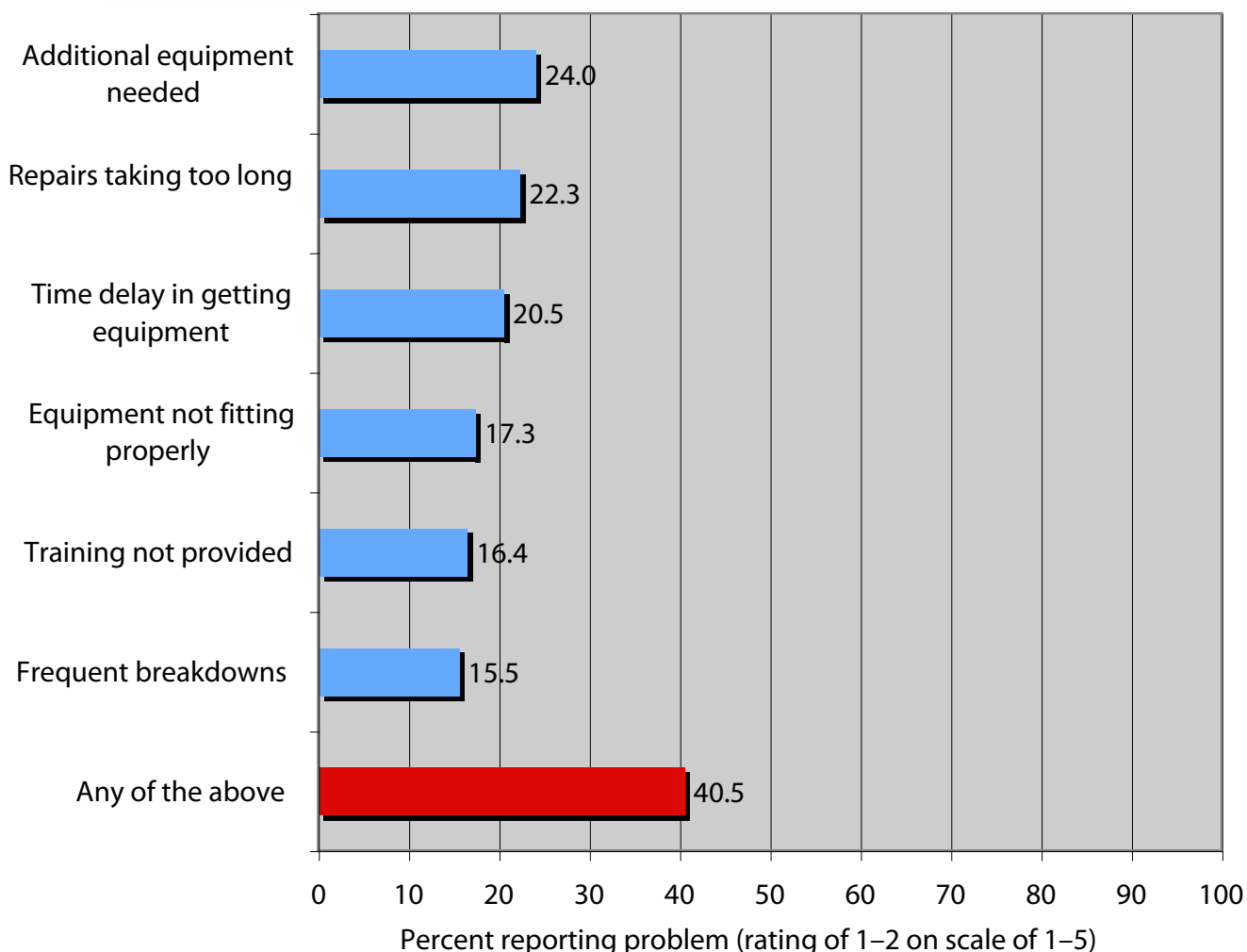
## Problems with AT as a barrier

Thus far, we have determined that there is a significant unmet need for assistive technology and examined the two top reasons (money and information) for that unmet need. Now let's look at the problems that the respondents experienced with their AT. Sometimes, after going through the steps needed to get the equipment, problems arise with the device upon use, or the equipment proves insufficient or takes too long to arrive.

We asked respondents to rate problems with

their AT devices on a scale of 1 (big problem) to 5 (not a problem). We considered it a significant problem if the rating was a 1 or 2. We listed a number of problems that had been raised earlier in focus groups. The result was that 41 percent indicated that they experienced one or more of the problems listed. While the numbers are not large, they do indicate which types of problem people are more likely to experience. These include additional equipment needed (24 percent), repairs taking too long (22 percent) and time delay in getting equipment (20 percent).

### Significant problems experienced with AT devices



### **Additional equipment needed**

Often, when one changes a wheelchair, for example, this may affect how transfers are made: Are bathrooms, doorways and hallways at home still useable? Does the change impact the method of transportation the consumer uses? Going from a manual chair to an electric one will demand that other equipment and processes be changed. One change can have a ripple effect across the consumer's environment, which must be planned for or the equipment may not be used. Professionals who are knowledgeable about AT must work with the consumer to look at the entire environment where the device will be used. Both must also be aware of the "accessories" that are needed to make the equipment easier to use and more comfortable, such as cushions, the correct foot rest, joy stick, etc.

### **Repairs taking too long**

Planning for repairs is critical for any device. Persons using augmentative communication devices lose their "voice" if their device goes in for repairs. Those who use wheelchairs often cannot get out of bed, let alone go anywhere (such as go to work) without a backup chair. Repairs that cannot be made quickly, effectively "disable" the individual all over again. In *How it Works: AT Narratives from California*, one individual tells the story of a wheelchair repair taking 6 months (p. 65); he described it as "taking half a year of my independence."

For a taste of what this is like, a person who relies heavily on computers to work can think back to when that computer was "down" and

waiting for the repair person to come. That same feeling of helplessness and frustration gives one a small clue as to what people with disabilities experience when their device is "down." So backup equipment has to be identified and purchased if needed. Repair shops and equipment loan programs should work together to ensure that back up equipment is available,

### **Time delay in getting equipment**

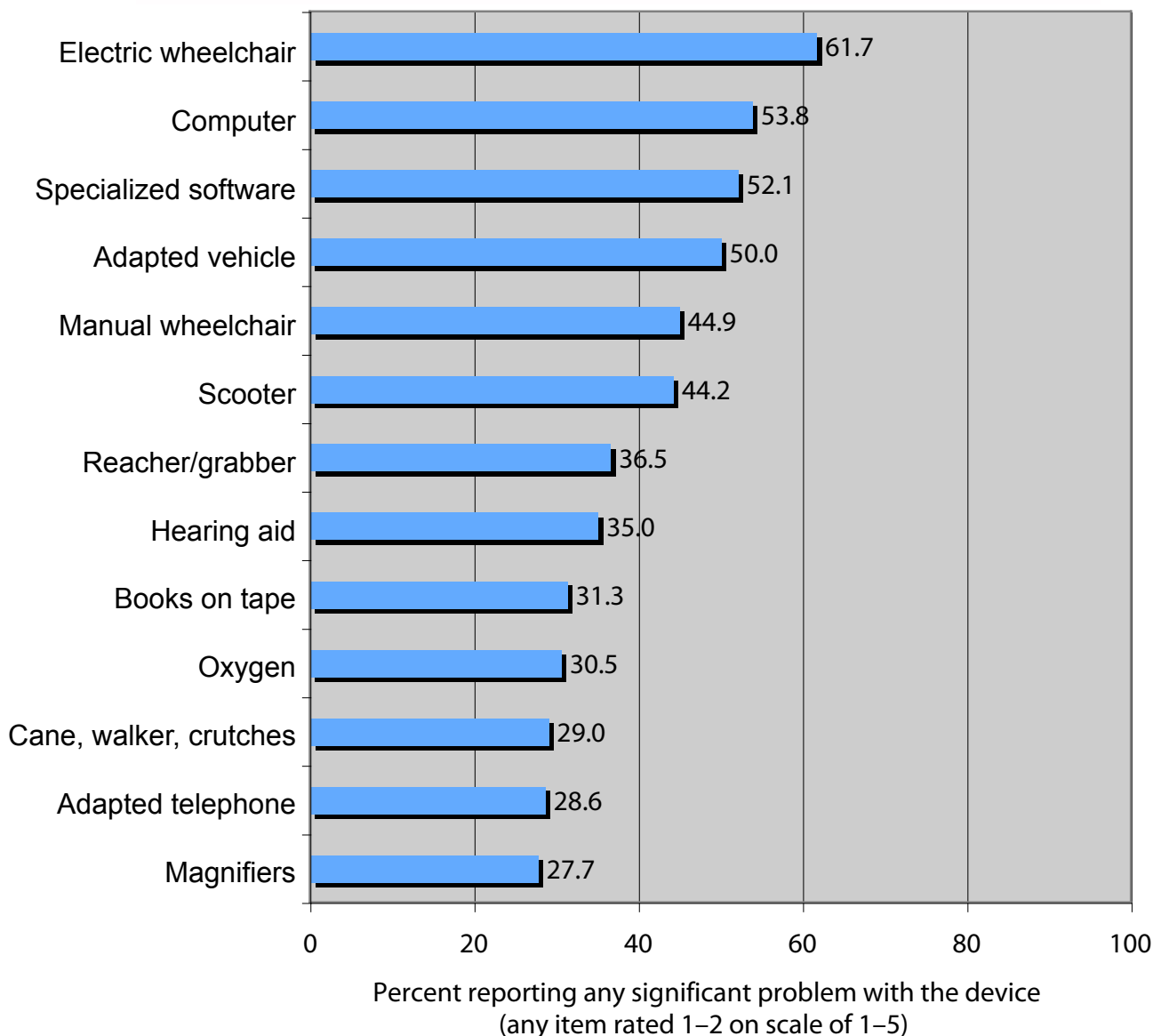
When the decision has been made as to what equipment should be used, it is exciting. The possibilities that equipment could make available are greatly anticipated. But waiting a long time is very frustrating. For those who are waiting for replacement equipment, a long wait means he/she may not be living as independently as could be or is not as productive. It is time wasted for that individual.

## Extent of problem by device

When asked about the extent of problems respondents had with their equipment, it became apparent that those who used complex equipment had more problems than those who used simpler equipment. The most problematic devices were electric wheelchairs (62 percent reporting a significant problem in one or more areas), computers (54 percent), specialized software (52 percent) and adapted vehicles (50 percent).

Simpler equipment such as magnifiers (28 percent) and adapted telephones (29 percent) seemed to have fewer problems, as might be expected.

**Extent of problems with common AT devices**

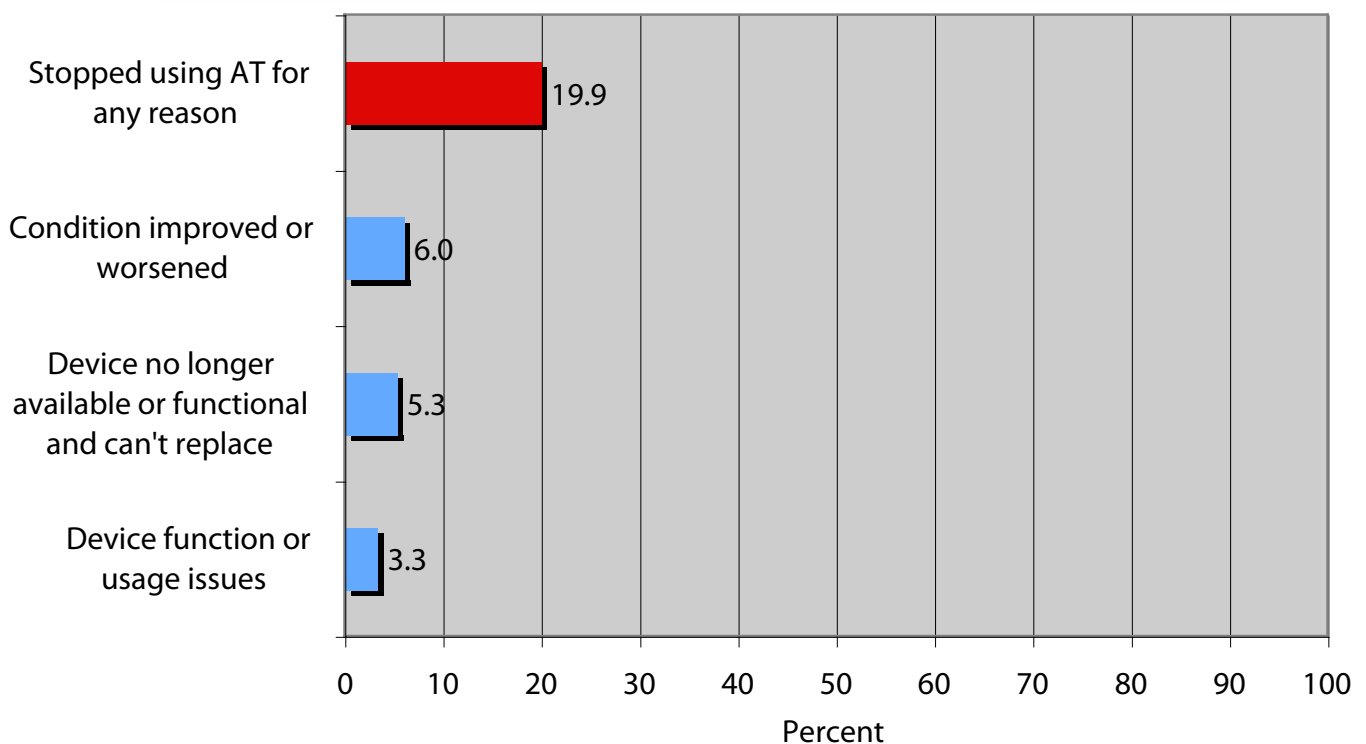


## Abandonment of equipment

In her 2005 book, *Living in the State of Stuck*, Marcia Scherer writes that, depending on the type of equipment, between 8 and 75 percent of equipment is abandoned for various reasons.

Respondents in this survey showed very different results. Surprisingly, just 20 percent of the entire sample indicated that they stopped using assistive technology for any reason. When asked why, changes in their condition were most likely to be mentioned. Given that many respondents, especially those paying for their own devices, were very likely to have participated in the choosing and purchasing of equipment, it is possible that this is one reason the abandonment of equipment was reduced.

**Reasons people stopped using their AT**

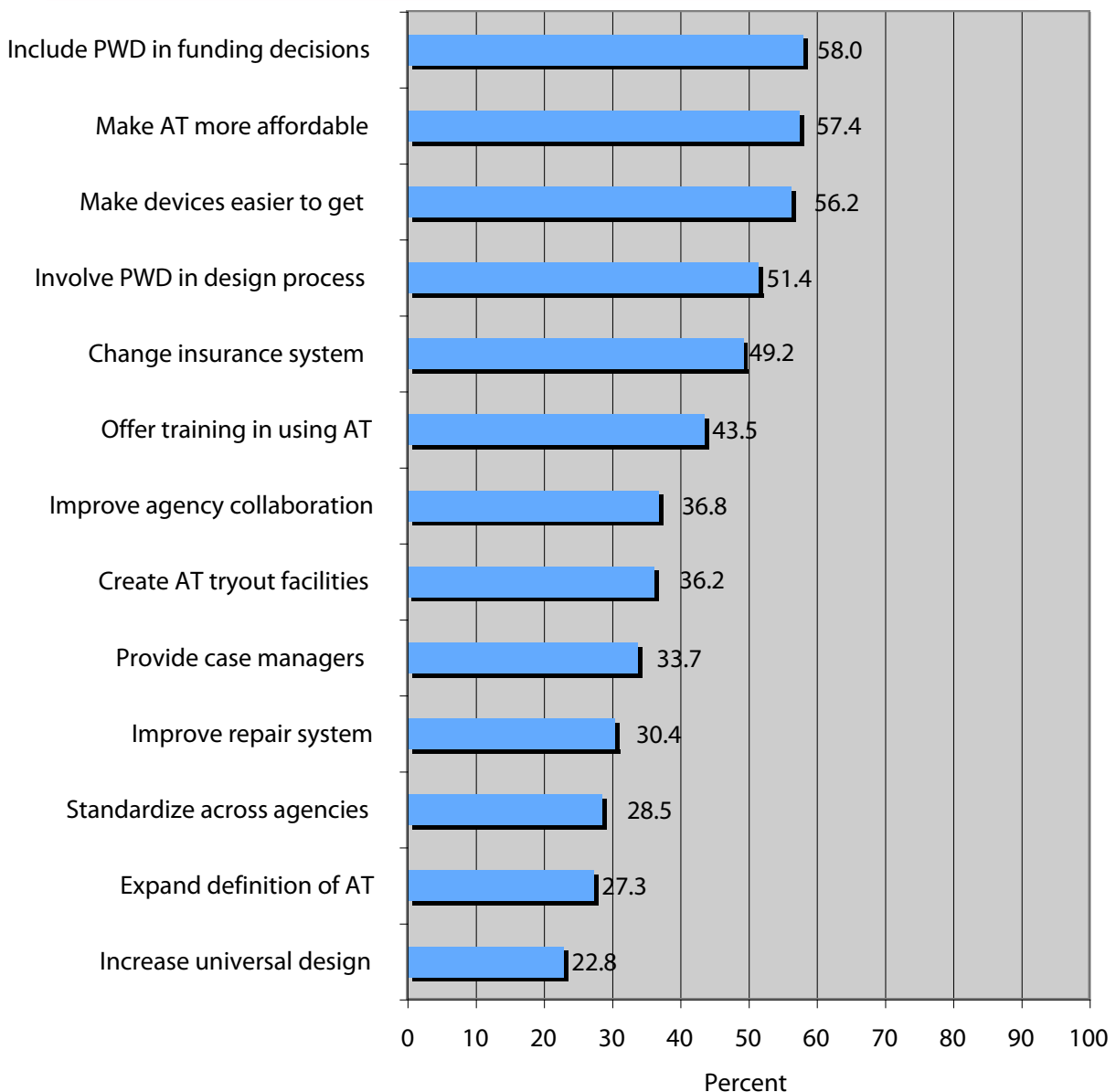


## How to “fix” the AT system

People with disabilities often develop very good problem solving skills out of necessity. They are the ones living through the experience and can usually point out improvements that could make things easier. When asked how the system could be improved, respondents were eager to have people like themselves involved in the decision-making process (58 percent). For those of us in the disability civil rights field, this is not

surprising. It follows the premise of “Nothing about us, without us.” If people who make decisions about funding (public policy makers, insurance folks, service delivery personnel) included people with disabilities who understood how vitally important it is to receive the right piece of equipment, quickly, with support on how to use it and a backup plan for when it fails, many problems could be avoided. Such a system would allow

**Consumer-desired changes to the AT system**



people to be more productive with much less “down” time.

Making AT more affordable (57 percent) and easier to get (56 percent) are two themes that have been mentioned in this project’s literature review and in the focus groups, and are now showing up in the quantitative research piece as well. This speaks to increasing the public investment in equipment and to getting providers and payers to coordinate their work.

However, a bit surprising was the suggestion that people with disabilities be involved in the design process (51 percent). This could be a nudge for the manufacturers and designers to develop ways for consumer input into their products. Such activity should result in a win-win situation for all involved; those who make and sell the equipment might have more desirable items leading to more sales, and people with disabilities might get equipment that better meets their needs. It also may be a different way to talk about universal design. Designing and building structures and equipment, so that there is less of a need to adapt it for individual usage, is a more cost-effective means to creating access and integration.



## **Changing the system: consumer share of cost**

Not content to just ask how the system could be changed, we also asked if the respondent would be willing to pay a share of cost if that would speed up the process. If so, how much would they be willing to contribute? Some 60 percent of the respondents indicated that they would be willing to pay a share of cost, 15 percent said no and 26 percent were not sure, perhaps wanting to know how much such a payment might be. When presented with ranges of payments, 64 percent indicated they would be willing to pay up to \$99 and 26 percent said between \$100 and \$499.

We cannot stress enough how low the annual income is for this set of respondents. Even with a high level of education, the median income is just \$10,000 to \$15,000 annually. So many individuals are already paying for some of their equipment; requiring a co-pay for those on the lower end of the scale will be a hardship that may keep many from getting the equipment they need to be fully functioning and contributing members of their community.

## Conclusions

Californians with disabilities from across the state who use Independent Living Centers have shared their perspectives on the unmet need for assistive technology and on barriers to AT usage. From the sample of 1900 respondents, 845 people have indicated they have unmet needs for equipment. Individuals with sensory disabilities and those who cannot walk report the most unmet need, while those with cognitive and mental health disabilities report the least. The more education one has, the more equipment one uses and the more aware he/she is of additional equipment that is needed. However, even those with little education knew of equipment they could use but didn't have.

There are no surprises as to why people don't get the equipment they need. Money and information have been barriers since equipment has become more widely available. Public healthcare programs (Medi-Cal and Medicare) generally pay for "medically necessary" equipment that maintains basic life needs. But true quality of life equipment, which makes independence and community participation possible, is paid for by the consumer and/or the family for the most part. The Department of Rehabilitation, a federally funded program that is perceived to be a major purchaser of this sort of equipment, plays only a minor role in funding AT for California ILC consumers, thus shifting the responsibility to those who have the least income to pay for it.

The equipment that respondents need but don't have ranges from small items such as magnifiers to costly vehicle modifications. Computers and hearing aids were frequently

mentioned. Typical costs for such devices range from free (indicating lack of knowledge of how to find or obtain it) to as much as \$52,000 for an extensively modified van. While individuals and their families may be able to pay for some items, clearly assistance is needed for the more costly ones. The benefit far outweighs the cost. Providing assistance, even on a sliding fee scale, is far better than leaving people to do without and languish at home waiting for a government benefits check.

Home modifications were also frequently mentioned and deserve a more in-depth look. Such modifications to housing can be individually tailored, but can also be taken care of through the modification of housing stock by builders and apartment managers. Thoughtful public policy that requires building universal design into living structures that are newly built or remodeled will, over time, reduce the need for individuals or public/private programs to pay for this type of equipment.

Other studies have shown a high rate of abandonment of equipment that makes one wonder if spending money on this need is good public policy. This study of adults who, theoretically, had more control over choice because they were paying for more of the cost, showed a markedly lower rate of abandonment and dissatisfaction. And in spite of having very low incomes, consumers were the top payer for equipment, indicating a very high value on such equipment. If that unmet need were to be met, productivity and participation would increase.

The other major barrier to getting the equipment needed was information. Making sure consumers know what exists and what works for each individual situation is going to take smart strategies and a working relationship between healthcare providers, disability organizations and other channels of information traditionally used by people of different ethnic and racial backgrounds. Respondents are searching for information, while relying on health care professionals who generally only tell them about life-sustaining equipment. A substantial number of people with disabilities have no involvement with disability organizations and don't come in contact with others who have disabilities, so it is difficult for disability agencies to address the huge need alone. Forging a respectful partnership between healthcare providers, disability service agencies and entities that serve minority communities, while increasing all three groups' knowledge base, may go a long way in addressing this need.

Adopting marketing strategies such as showing success stories of AT users of all backgrounds and various functional limitations will help others learn about equipment that might better serve them. Using general marketing venues such as bus, TV and print ads and stories, tapping minority communication channels and organizing information in websites that are easily accessible in multiple languages, will bring the information to consumers and their families as well as the general public.

Once people get the equipment they need and really start to improve their quality of life, it is very frustrating when they lose it all over again because of poor planning

and implementation. Anyone working with consumers on their AT needs must consider planning for additional equipment that may be needed, shortening repair time and shortening the time to get equipment delivered. In other words, a "plan B" needs to be developed so that loaner and/or replacement equipment can be quickly delivered; doing this will lessen the downtime consumers often experience when their AT is removed.

Respondents to the survey were very clear about how they would like to see the AT System changed to be more effective. Having individuals with disabilities in decision-making roles about funding, making funding more available, making equipment easier to acquire and having people with disabilities working with designers and manufacturers of equipment are four sure-fire ways to improve access to assistive technology that truly promotes independence.

As more people age into having a disability, survive catastrophic injuries or come back from wars with significant disabilities, we need to put more funding into assistive technology. Funding for both the "medically necessary" as well as the independent living and community participation equipment will help make or keep people functioning in their community. Loans, co-pays and means tests will help stretch the funding to reach more people.

As more funding becomes available through public and private sources, the need for good information at people's fingertips will increase. Finally, those who use or could use the equipment must be connected

to the designers and manufactures of the equipment so that the user's needs are met, lessening the likelihood of abandonment.

## *Chapter 5*

# **The Benefits of Assistive Technology**

People with disabilities derive substantial benefit from the technology they use. AT enables people to engage in a great many activities at home, in their communities, and while at work and school. Technology allows people not only to stay alive and maintain their health, but also to participate actively in social and economic life, and to be more fully integrated members of their community.

In this chapter, we present data showing that Independent Living Center consumers who

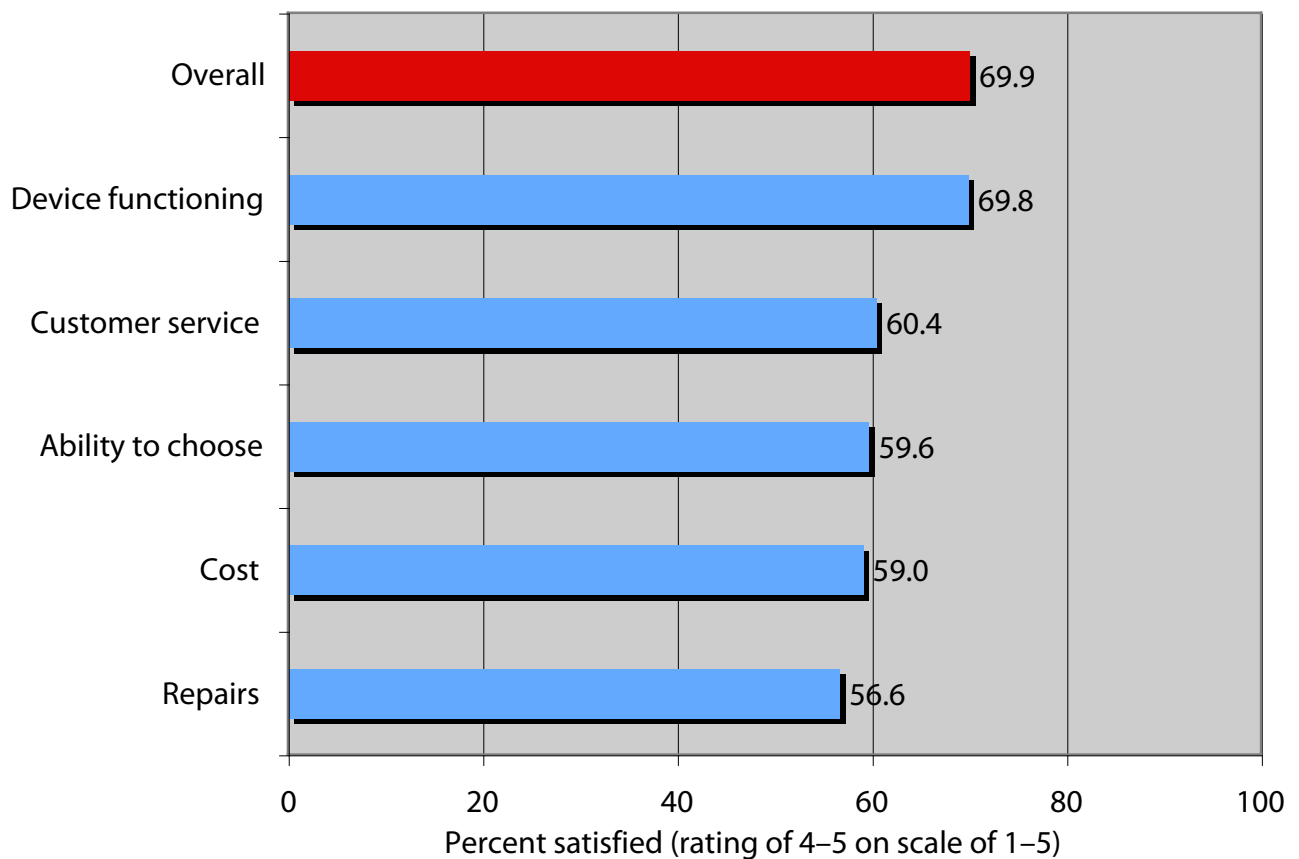
use AT are by and large quite satisfied with their devices. It is apparent, however, that some devices perform better than others, and there is some degree of dissatisfaction with the cost of certain devices and the repair process of others. We also offer evidence of the wide variety of activities that AT users engage in, and of the crucial role that assistive technology plays in reducing the problem of social isolation among people with disabilities.

## How satisfied are people with their Assistive Technology?

Survey respondents who used AT were generally highly satisfied with their devices. Asked to rate their overall satisfaction of their primary and secondary AT devices on a scale of 1 (very dissatisfied) to 5 (very satisfied), the average score was 4.0, and 70 percent of devices were rated 4 (satisfied) or 5 (very satisfied). When rating specific aspects of their devices, the highest marks were for the way the device functioned (70 percent

of devices rated 4 or 5). Fairly high ratings were also given for the help the person got in finding, selecting, and using the device (60 percent satisfied with “customer service”), for the ability to choose the device (60 percent), and for the cost of the device (59 percent). The lowest score was for repairs, with only 57 percent of devices rated 4 or 5, excluding devices not subject to repair.

**Satisfaction with aspects of AT devices**

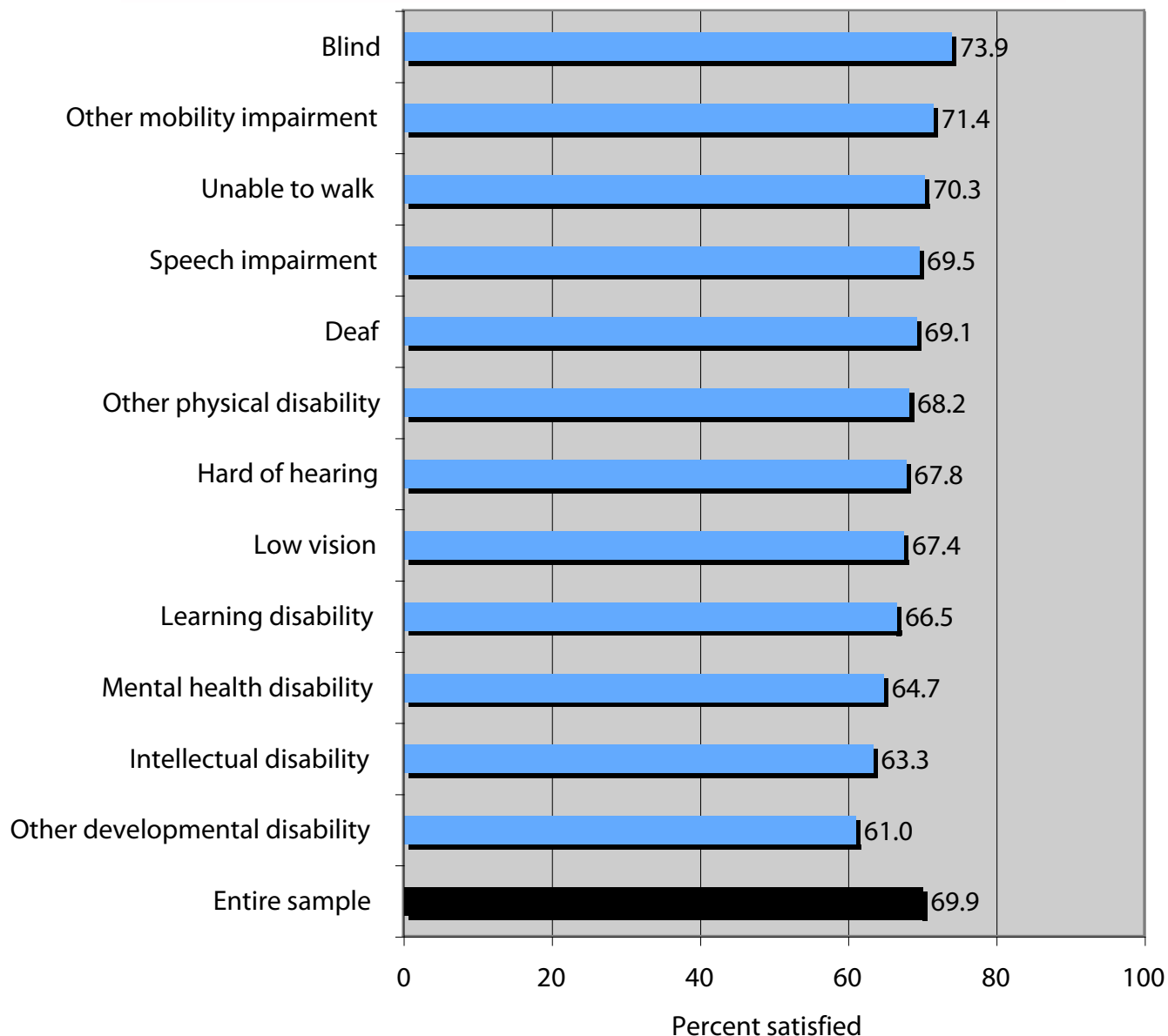


## Satisfaction among different disability groups

Satisfaction is generally high across disability categories. Roughly 70 percent of devices used by people with all types of sensory, mobility, other physical, and speech impairments received overall satisfaction scores of 4 or 5 (on a scale of 1 to 5). There is some evidence, however, that people with cognitive or mental health disabilities are less

satisfied with the devices they use, with only 61–65 percent of devices used by people with intellectual disabilities (i.e., mental retardation), other developmental disabilities, and mental health disabilities getting scores of 4 or 5.

**Satisfaction with assistive technology, by disability type**

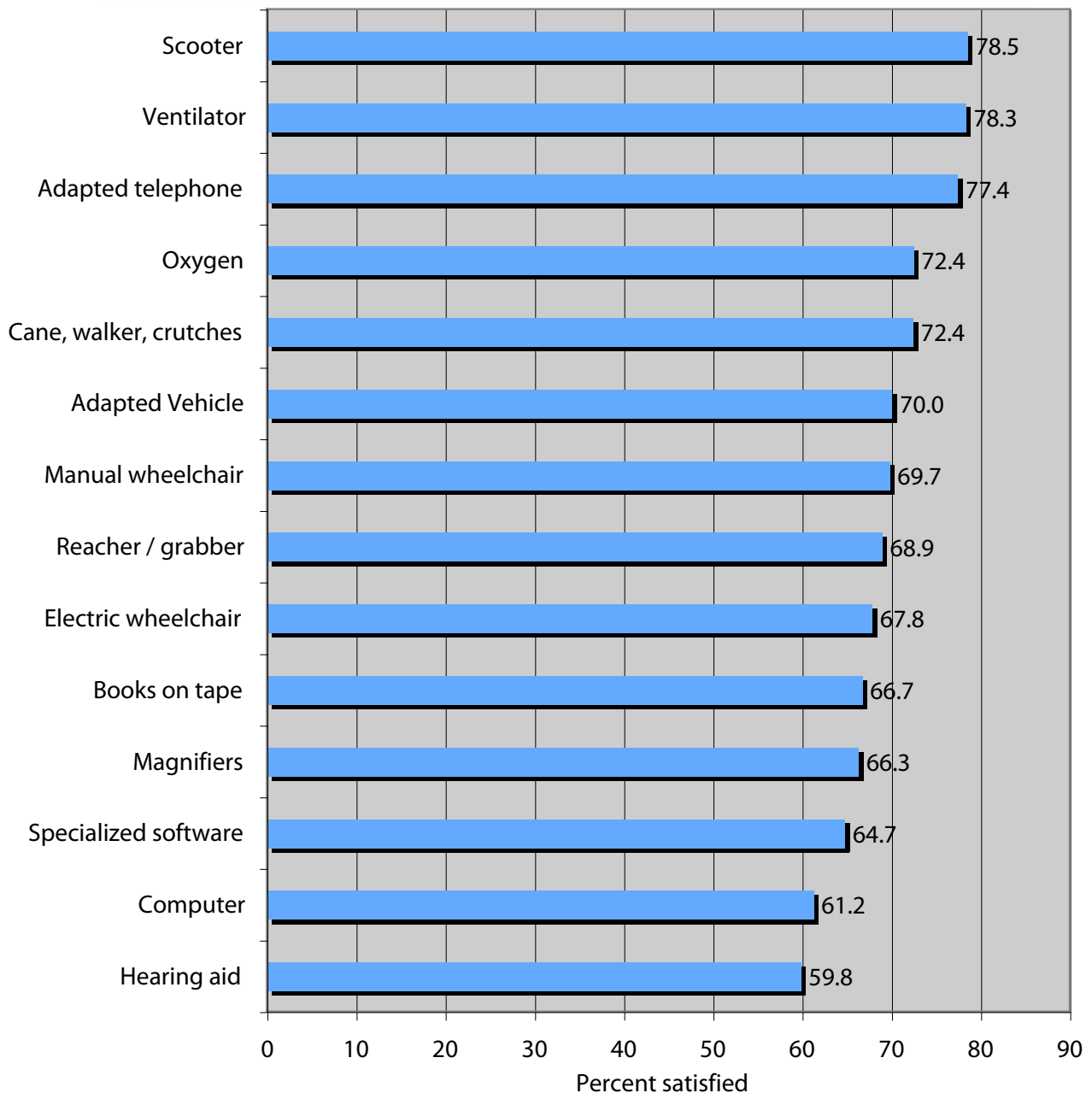


## Overall satisfaction with common AT devices

Looking at satisfaction with specific devices, we find a range of between 60 percent to nearly 80 percent satisfaction. Users of scooters (79 percent), ventilators (78 percent), and adapted telephones (77 percent) report the highest level of satisfaction. At the opposite extreme are users of hearing aids (60 percent satisfied) and

computers (61 percent). Other commonly used devices fall in the range of 65–72 percent satisfaction.

**Satisfaction with commonly used AT devices**





## Satisfaction with aspects of AT devices

This table shows the proportion of users of the more common AT devices who express satisfaction (again, a rating of 4 or 5 on a scale of 1 to 5) with specific aspects of those devices. Perhaps the most striking finding is that, across nearly all of these devices, a substantial majority of users are satisfied with the way the device functions. A majority of users of all devices are likewise satisfied with customer service and with their ability to choose the device. In contrast, only a minority of users of certain devices express satisfaction with either the cost of the device or the repair process.

Users of oxygen, scooters, and the category of canes, crutches, and walkers expressed the highest level of satisfaction with device

functioning (76–77 percent satisfied). Least satisfied with device functioning were users of specialized software (53 percent). Only 60 percent of computer users were satisfied, as were the same proportion of users of reachers and grabbers.

Scooter users were the most satisfied with the customer service they'd received (more specifically, with the help they'd gotten in finding, selecting, and using the device), at 70 percent. Users of hearing aids (69 percent), books on tape (69 percent), and ventilators (68 percent) were also quite satisfied. Least satisfied with customer service were those using computers (51 percent), specialized software (53 percent), and manual wheelchairs (54 percent).

<b>Satisfaction with specific aspects of common AT devices</b>					
	Functioning	Service	Choice	Cost	Repairs
	Percent satisfied				
Scooter	76.7	70.4	75.7	63.8	60.0
Ventilator	68.4	68.4	57.9	60.0	68.4
Adapted telephone	73.8	67.1	68.0	76.0	60.0
Oxygen	76.8	67.3	52.7	73.6	67.3
Cane, walker, crutches	76.2	63.3	63.2	70.5	65.0
Adapted Vehicle	65.0	63.4	62.5	37.5	31.6
Manual wheelchair	63.4	53.6	51.2	56.8	53.8
Reacher / grabber	60.3	58.2	50.7	59.4	52.9
Electric wheelchair	65.4	57.6	56.4	51.6	45.2
Books on tape	70.0	68.8	60.6	60.0	70.4
Magnifiers	73.7	63.0	66.2	66.2	59.3
Specialized software	53.1	53.2	60.0	40.8	46.2
Computer	60.3	51.2	57.5	42.6	45.8
Hearing aid	65.3	69.1	60.4	46.3	52.3

The highest satisfaction ratings for ability to choose were again reported by scooter users, at 76 percent. Also highly satisfied with their ability to choose their devices were adapted telephone users (68 percent) and magnifier users (66 percent). Least satisfied with this aspect were users of reachers and grabbers (51 percent) and manual wheelchairs (51 percent).

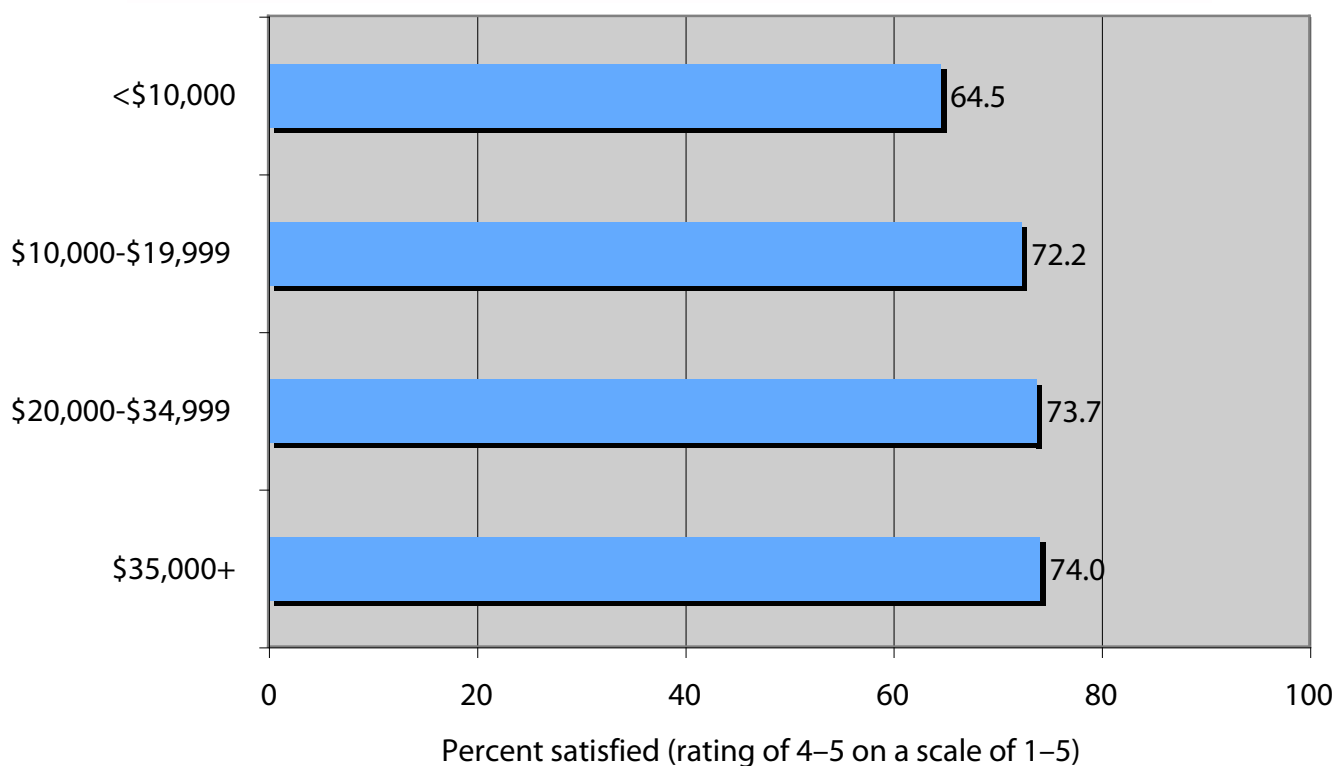
Users of adapted telephones, which qualified individuals can obtain for free through the state-run California Telephone Access Program, were the most satisfied with cost, at 76 percent. Those using adapted vehicles were the least satisfied with the cost (38 percent), followed by users of specialized software (41 percent), computers (43 percent), and hearing aids (46 percent).

Finally, when rating their satisfaction with repairs, users of books on tape (70 percent), ventilators (68 percent), oxygen (67 percent), and canes, walkers, and crutches (65 percent) were the most satisfied. At the opposite end of the spectrum were adapted vehicles, only 32 percent of whose users were satisfied with repairs. Also dissatisfied were electric wheelchair users (45 percent satisfied with repairs), computers (46 percent), and specialized software (46 percent).

## Satisfaction by income

Overall satisfaction with AT devices increases with income. In particular, device users with the lowest income levels were the least likely to be satisfied with their devices overall—only 65 percent of people with annual household incomes under \$10,000 were satisfied with their devices overall, compared to 74 percent of people with incomes of \$20,000 or above.

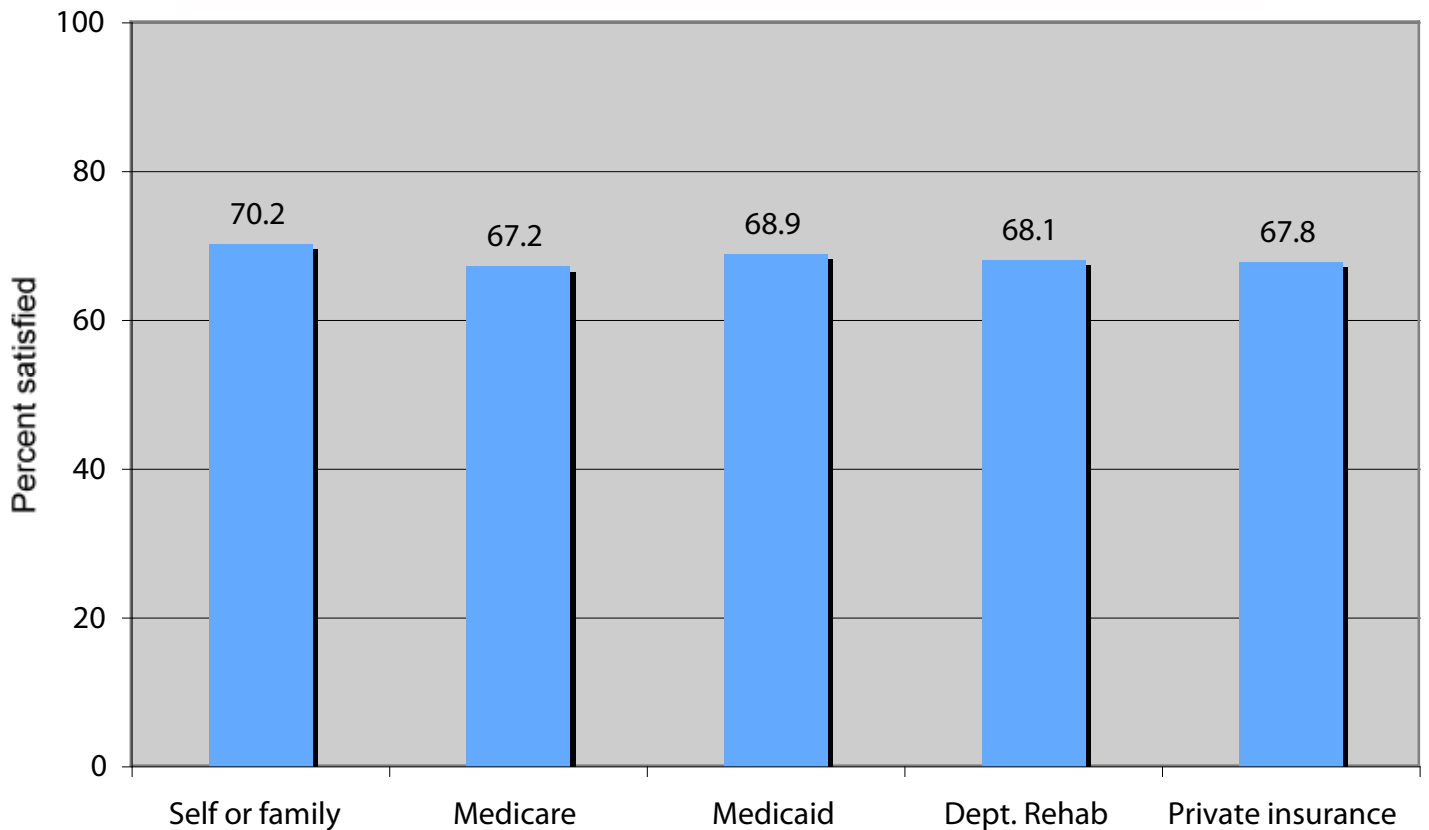
**Satisfaction with AT devices, by annual household income**



## Satisfaction according to source of payment

We can compare satisfaction among the major payers for AT devices. Surprisingly, there are no statistically significant differences in people's level of satisfaction with their AT devices according to who paid for them. Satisfaction levels range from 67 percent for devices paid for by Medicare to 70 percent for devices paid for by the respondent or his or her family.

**Overall satisfaction with AT device, by payer**

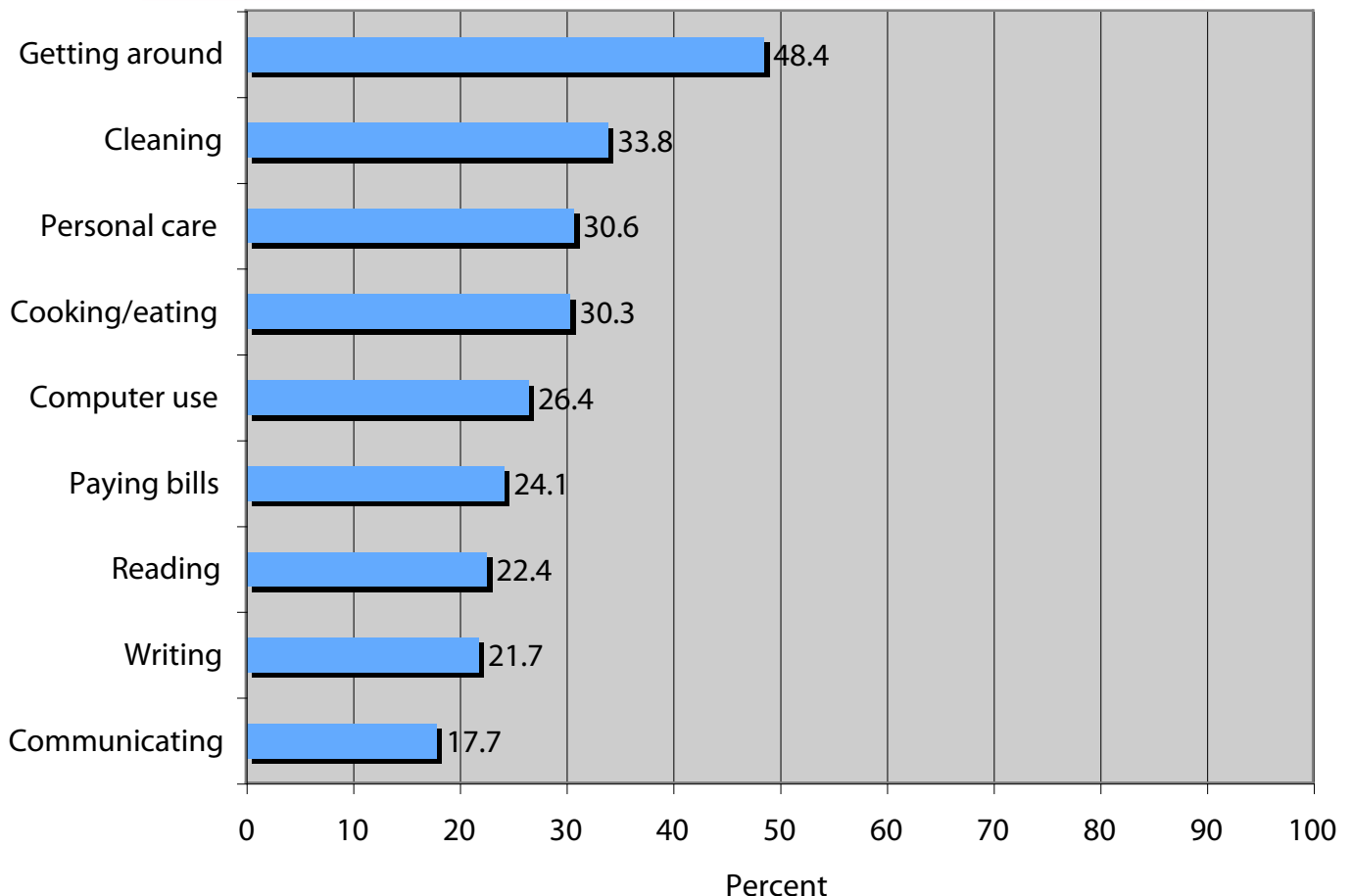


## What home and community activities does AT make possible?

People use their assistive technology to help them engage in a great many activities at home and in the community. These activities include routine, practical activities such as cleaning, taking care of one's personal needs, and going to the doctor—all activities essential for living, managing one's home, and maintaining one's health. People also use their AT for other, equally important activities that allow them to participate more fully in society, such as reading, communicating, and engaging in social activities.

When asked what home activities they need their AT for, nearly half of AT-using respondents said they needed their technology to get around. Roughly one-third reported needing AT for cleaning, personal care, or cooking and eating. About one-quarter needed AT to use the computer or to pay bills, and about one-fifth needed AT to read, write, or communicate.

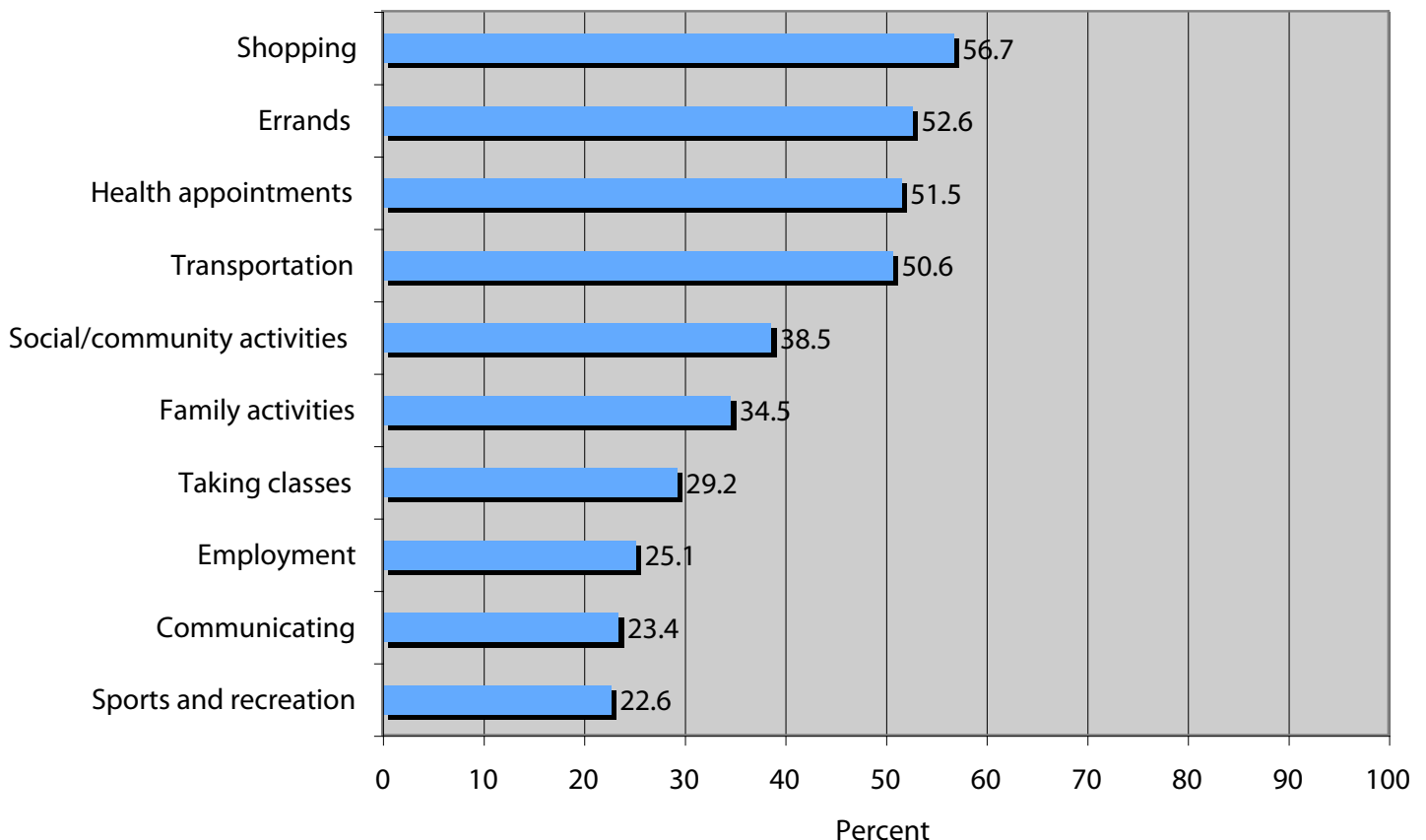
**Principal home activities enabled by AT, among AT users**



## Community activities

More than half of AT-using respondents need their devices to engage in each of the following practical activities in their community: shop, do errands, go to health appointments, or get around their community. AT also enables users to engage in community activities involving social participation to a substantial extent: Some 39 percent need AT to engage in social or community activities, 35 percent need AT to participate in family activities, 29 percent need AT to take classes, 25 percent to work, 23 percent to communicate while in the community, and 23 percent to engage in sports or other recreational activities.

**Principal community activities enabled by AT, among AT users**



## Participatory versus practical activities

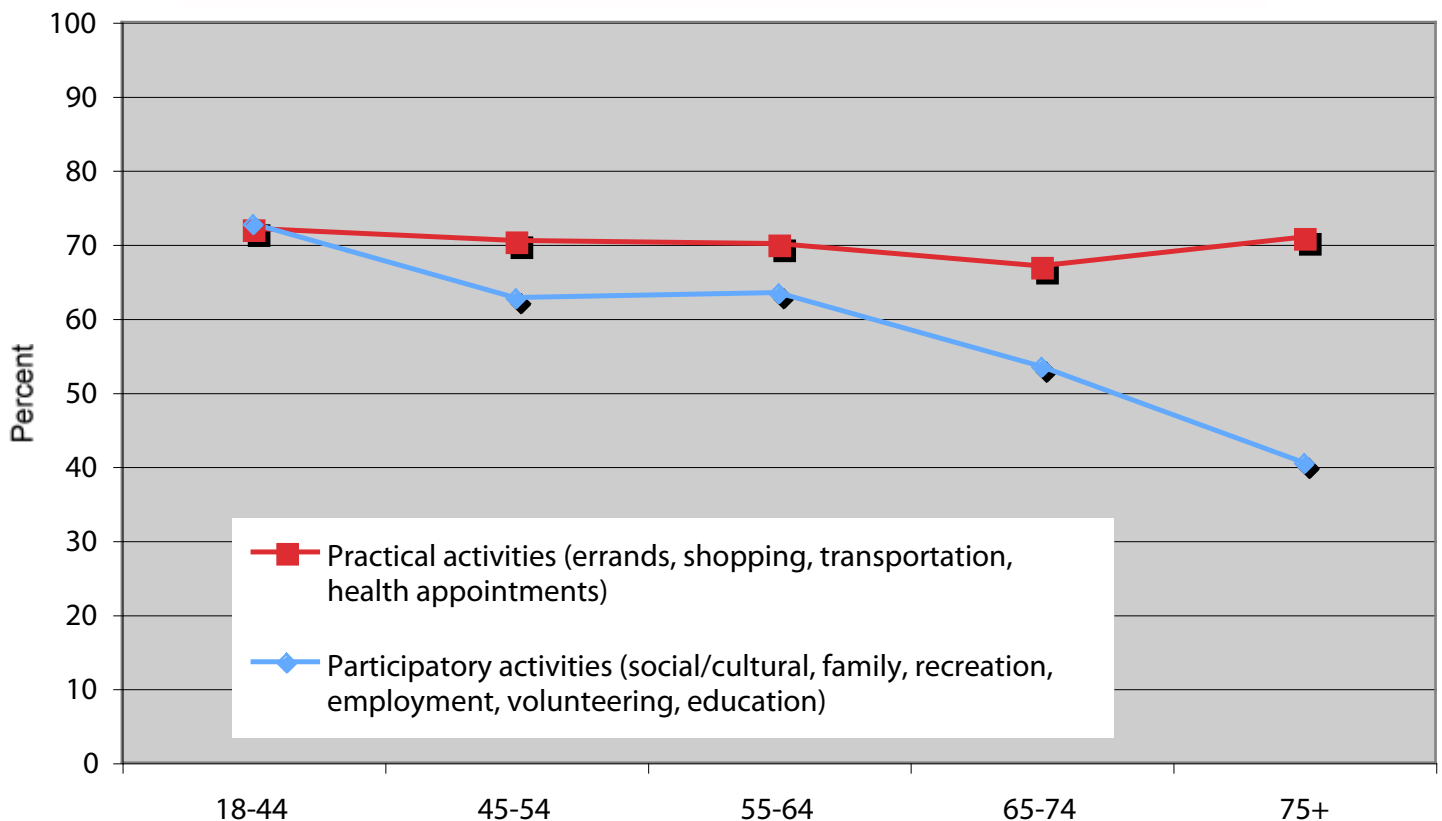
For respondents in every age category, a large majority of AT users use their devices to engage in practical activities, such as running errands, shopping, getting around the community, and receiving healthcare. Across the age spectrum, roughly 70 percent of AT users use their devices to perform such activities.

But the same is not true for participatory activities, including social, cultural, family, and recreational activities, as well as working, volunteering, and attending classes. For participatory activities, there is a steep decline with age in the proportion of AT users who use their AT to perform these activities. For younger adults (18–44), AT

enables 73 percent of device users to engage in such activities. That fraction drops to 63 percent for older working-age adults (45–64), and then continues to decline, dropping to only 40 percent for people 75 years of age or older.

This difference in the way AT is used between younger and older users probably reflects differences in the types of devices used by younger and older adults with disabilities. As shown in Chapter 3, older adults are much more likely to use low-tech assistive devices like canes and walkers, while usage of higher tech devices is greater among younger adults.

**Usage of AT for participatory versus practical activities, by age**



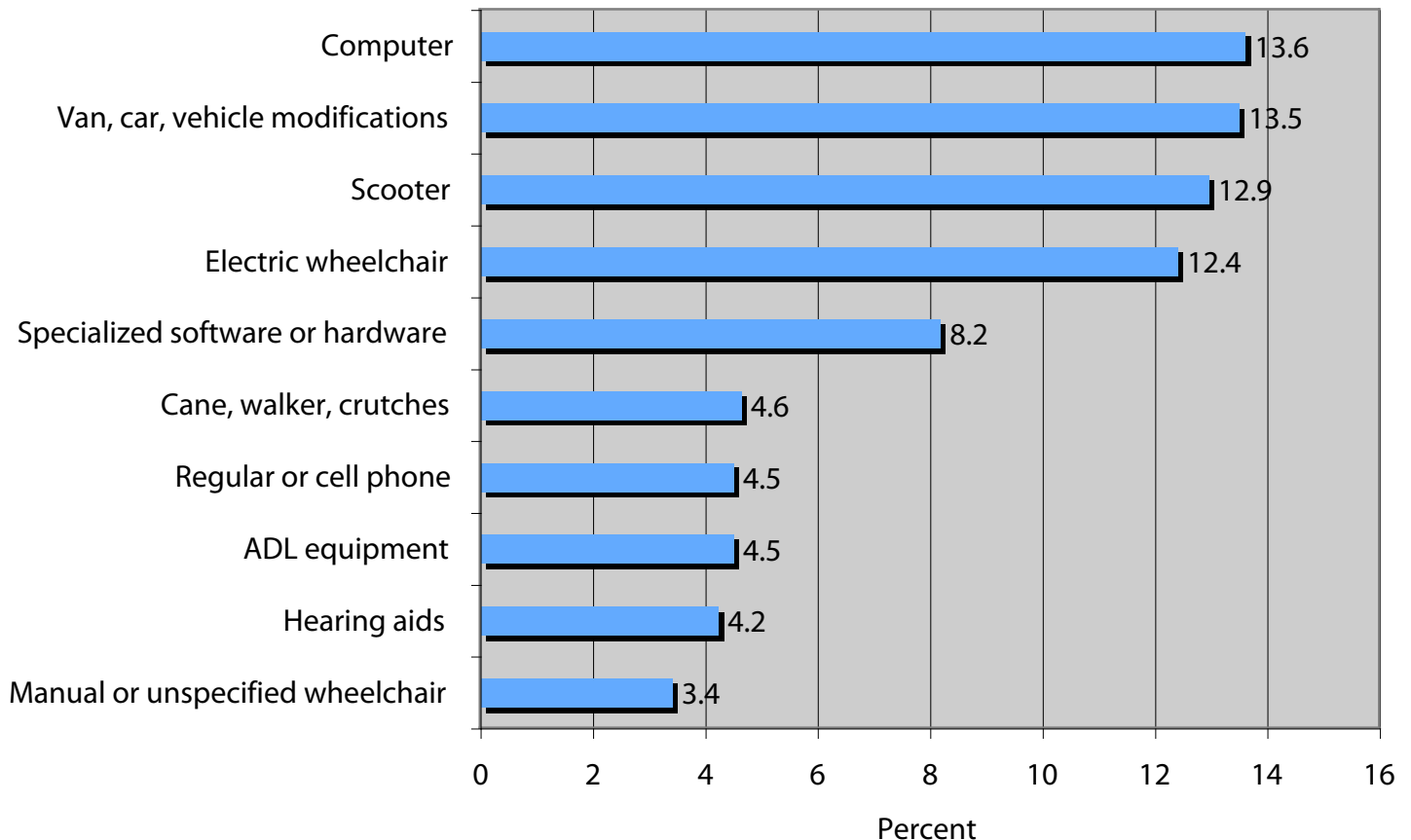
## What AT devices most enable independent living?

Respondents were asked to name an assistive technology device, one they might or might not currently possess, that would most help them to live independently. We grouped their verbatim responses into general categories, and found somewhat surprising answers for the top categories: 14 percent of respondents answering the question named a computer as the device that could (or did) most help them live independently, and an equal percentage said that a van or car, or modifications to a van or car (e.g., hand controls, a ramp, or a lift), would be most helpful. In both cases, these

are not the kinds of equipment that would be deemed “medically necessary” or paid for by Medicare or Medicaid, but instead devices that contribute to a person’s ability to participate more fully in society.

Scooters (13 percent) and electric wheelchairs (12 percent) were the next most frequently mentioned devices. Others included specialized computer software or hardware, telephone equipment, devices to help with self-care activities, and hearing aids.

**AT devices considered most helpful for living independently**





## Most helpful device by type of disability

Among people with more severe limitations in mobility (people who said they “can’t get around without help or equipment”), the category of device most often mentioned as most beneficial to living independently was a van, car, or a modification to a van or car. Among those with lesser mobility impairments, scooters were most often mentioned. People with other types of physical disabilities (often chronic illnesses) also mentioned scooters, but computers were mentioned equally often.

Computers and related technology were mentioned most often by several other disability groups: blind people, who specifically mentioned specialized software or hardware such as screen magnifiers, screen

readers, and scanners; regular computers were most often mentioned by people with low vision, speech impairments, intellectual or developmental disabilities, learning disabilities, and mental health disabilities. People who were deaf or hard of hearing mentioned hearing aids most often as devices that could best promote living independently.

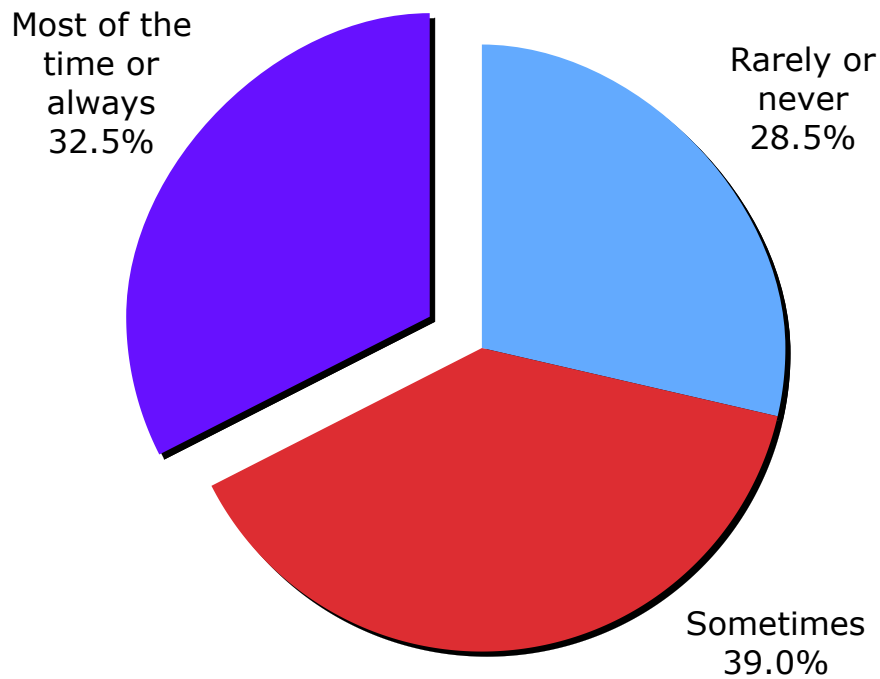
Again, most of these groups are citing equipment not traditionally regarded as “medically necessary” and therefore not paid for by public healthcare programs. Yet consumers regard these devices as essential in enabling them to live independently in the community and participate in society.

<b>Devices cited as most helpful for living independently, by type of disability</b>	
<b>Type of disability</b>	<b>Device most often mentioned</b>
Unable to walk	Van, car, vehicle modifications
Other mobility impairment	Scooter
Other physical disability	Scooter / Computer (tie)
Blind	Specialized software/hardware
Low vision	Computer
Deaf or hard of hearing	Hearing aids
Speech impairment	Computer
Intellectual/developmental disability	Computer
Learning disability	Computer
Mental health disability	Computer

## How does AT relate to social isolation?

We presented respondents with the statement, "I feel isolated due to my disability," and asked them to tell us how often that statement was true. Just over one-third said "most of the time" or "always" and 39 percent said "sometimes." Only 28.5 percent said they "rarely" or "never" felt isolated due to their disability.

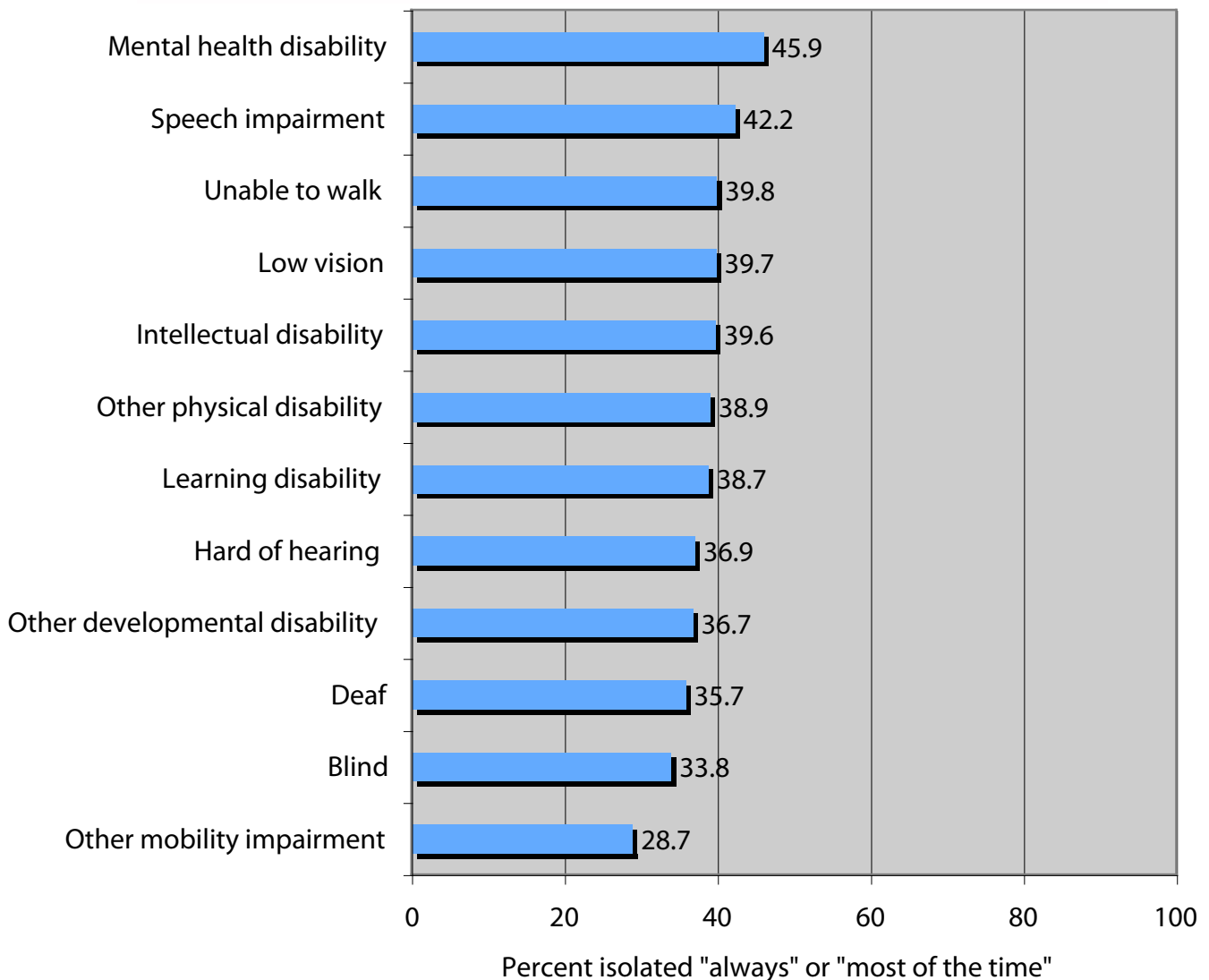
**Feelings of isolation due to disability**



## Social isolation among different disability groups

People with mental health disabilities have the highest rates of social isolation, with 46 percent reporting that they are isolated due to their disability “most of the time” or “always.” People with speech impairments, more severe mobility impairments, low vision, intellectual disabilities, other physical disabilities (i.e., chronic illnesses), and learning disabilities also report high levels of social isolation, with roughly 40 percent of each group experiencing frequent isolation.

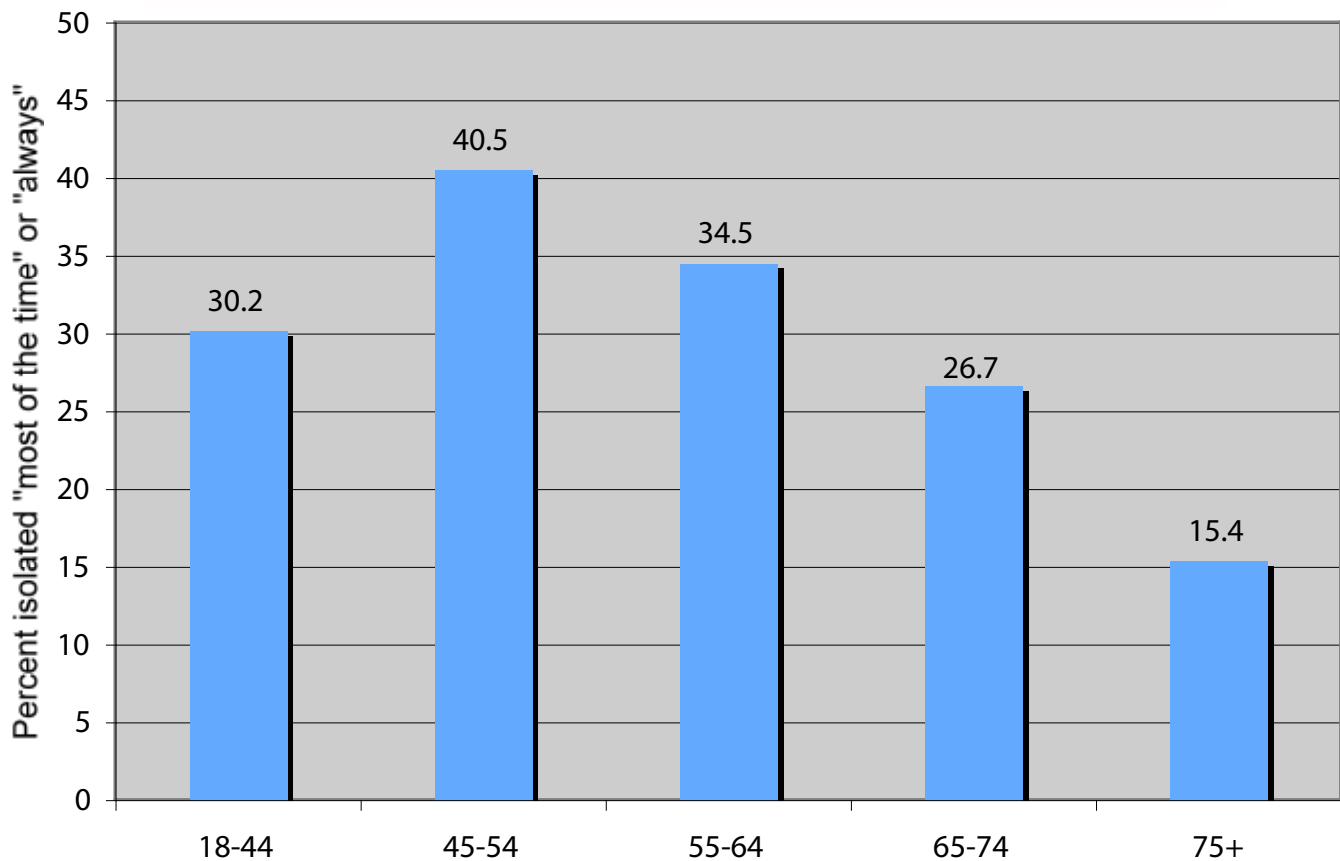
**Frequent social isolation, by disability type**



## Social isolation by age

Much has been written about social isolation among elderly Americans, but our data shows that non-elderly respondents with disabilities are much more likely than their older counterparts to report frequent social isolation. Highest levels of social isolation are reported by respondents in the age range of 45–54 (41 percent feeling isolated most of the time or always), and that rate drops steadily with age to a low of 15 percent for people age 75 or over. Although younger adults (18–44) report less isolation than their slightly older counterparts, some 30 percent experience frequent social isolation.

**Frequent social isolation, by age group**



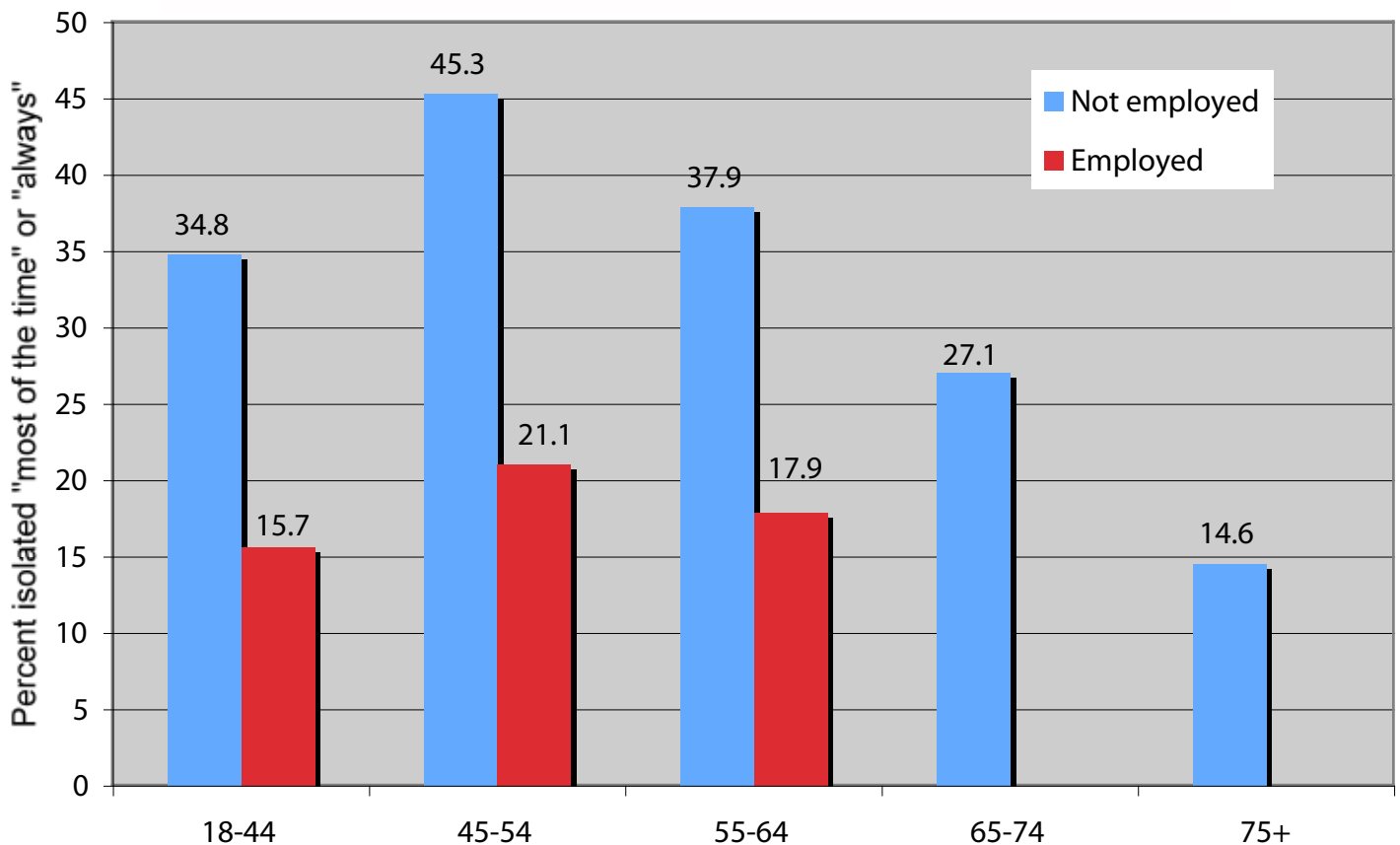
## Social isolation and employment

One reason for social isolation among our respondents who were under 65 years of age is that so few of them were employed, in contrast to most of their peers without disabilities. Indeed, when we compare levels of social isolation for working-age adults who have jobs with those who don't, we find dramatic differences. For example, for the 45–54 age group, only 21 percent of those who work experience frequent social

isolation, versus 45 percent of those who are not employed. Only 16 percent of younger respondents (18–44) who work are socially isolated, compared to 35 percent of those not working.

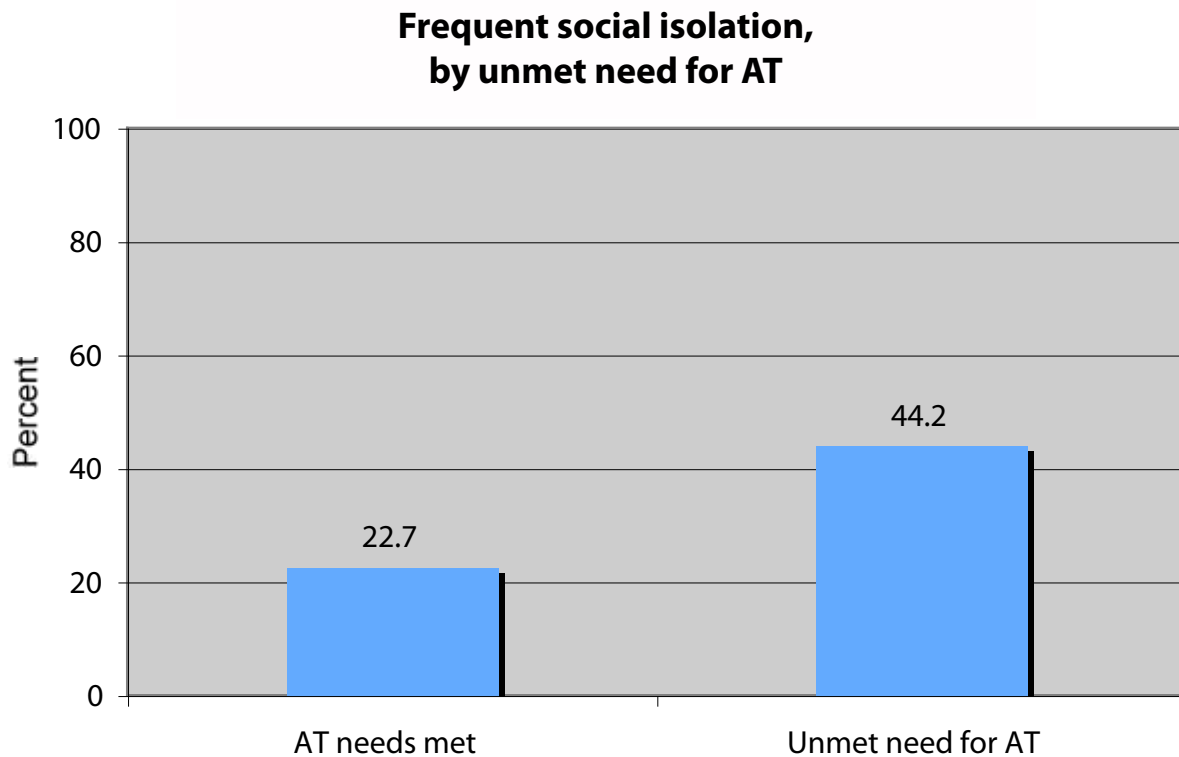
Having a job appears to be a crucial way of making social connections and preventing isolation among working-age adults with disabilities.

**Frequent social isolation, by age & employment status**



## Social isolation and unmet need for AT

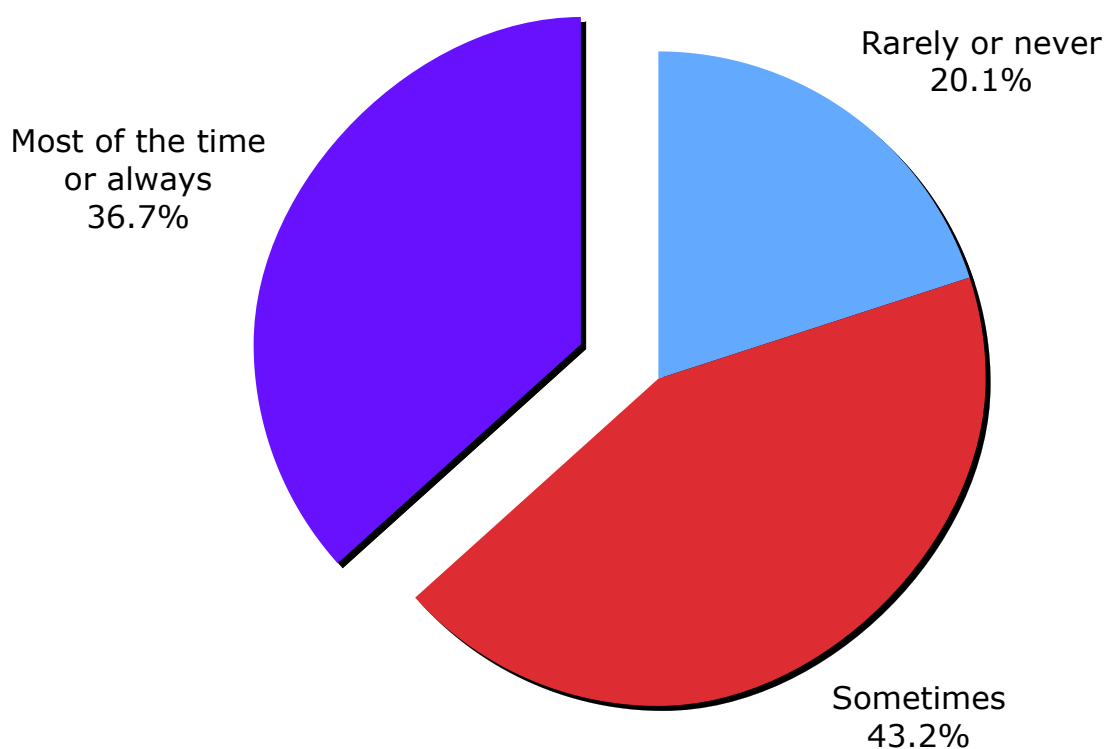
Assistive technology also makes a dramatic difference in the level of social isolation that respondents experience. People who said they had all of the AT that they needed were about half as likely to report frequent social isolation as people who had unmet need for AT—23 versus 44 percent. This is one of several findings in our study that highlight the crucial role that AT plays in promoting social integration among people with disabilities.



## The relationship of AT to social isolation

We asked people explicitly about the relationship between their usage of AT and social isolation. For respondents who used AT and reported feeling isolation at least sometimes, we asked whether using AT helps them cope with feeling isolated. Of those responding, 37 percent said that their AT helps them cope with isolation “most of the time” or “always.” An additional 43 percent said “sometimes.” Only one-fifth of respondents (20 percent) said that their AT “rarely” or “never” helped them cope with isolation.

**Extent to which AT helps cope with isolation,  
among AT users experiencing isolation**

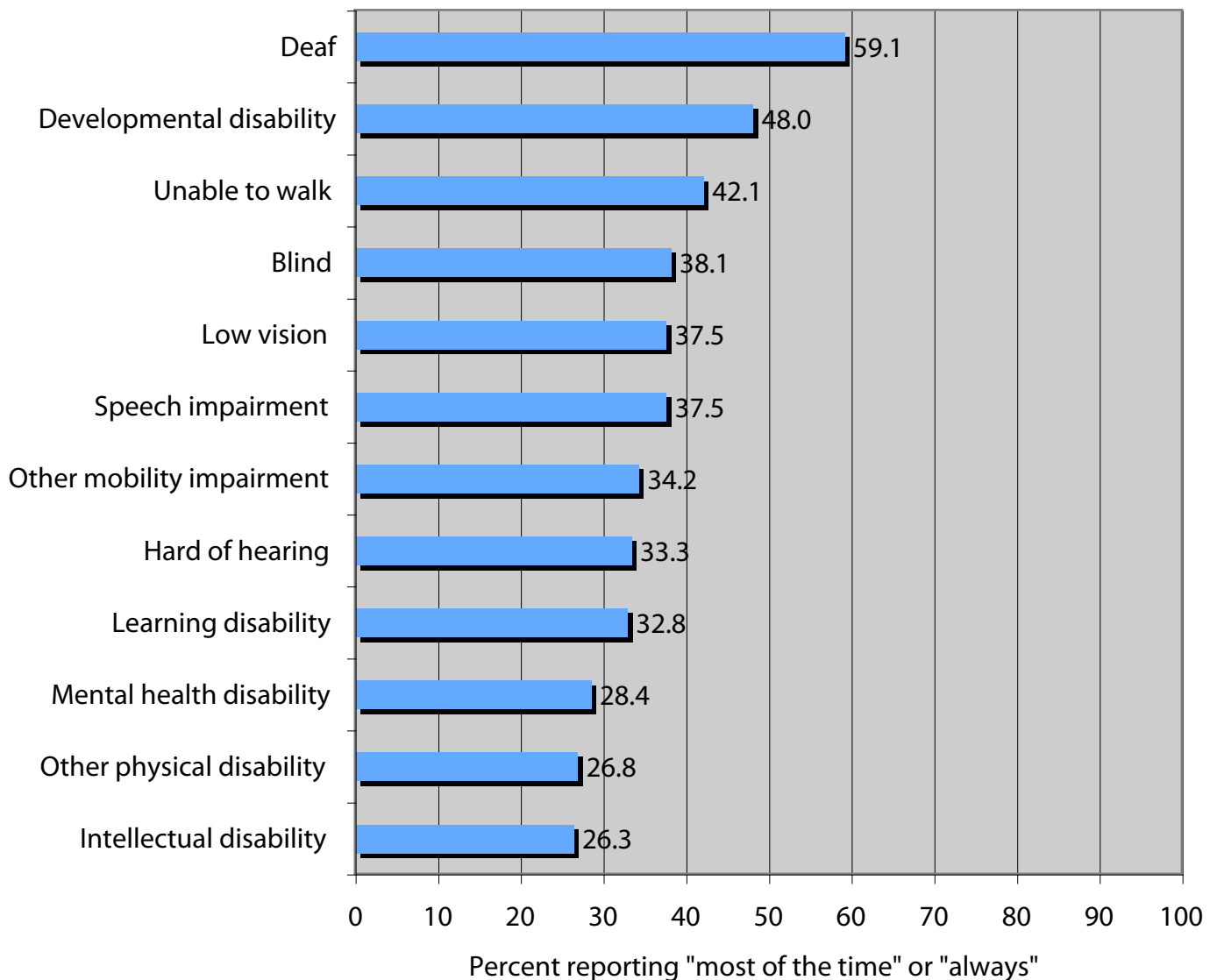


## AT and social isolation, by disability group

Of all disability groups, deaf respondents were the most likely to report that their AT usually helped them cope with social isolation (59 percent responding “most of the time” or “always”). Second were people with developmental disabilities (excluding intellectual disabilities), 48 percent of whom said their AT usually helped them cope. People with more severe mobility impairments

were next at 42 percent, followed by people who were blind or had low vision or speech impairments, all at 38 percent. AT users with intellectual disabilities, with other physical disabilities, or with mental health disabilities were least likely to report this benefit from their AT (26–28 percent for each group).

**Proportion of AT users whose AT usually helps cope with social isolation, by disability type**

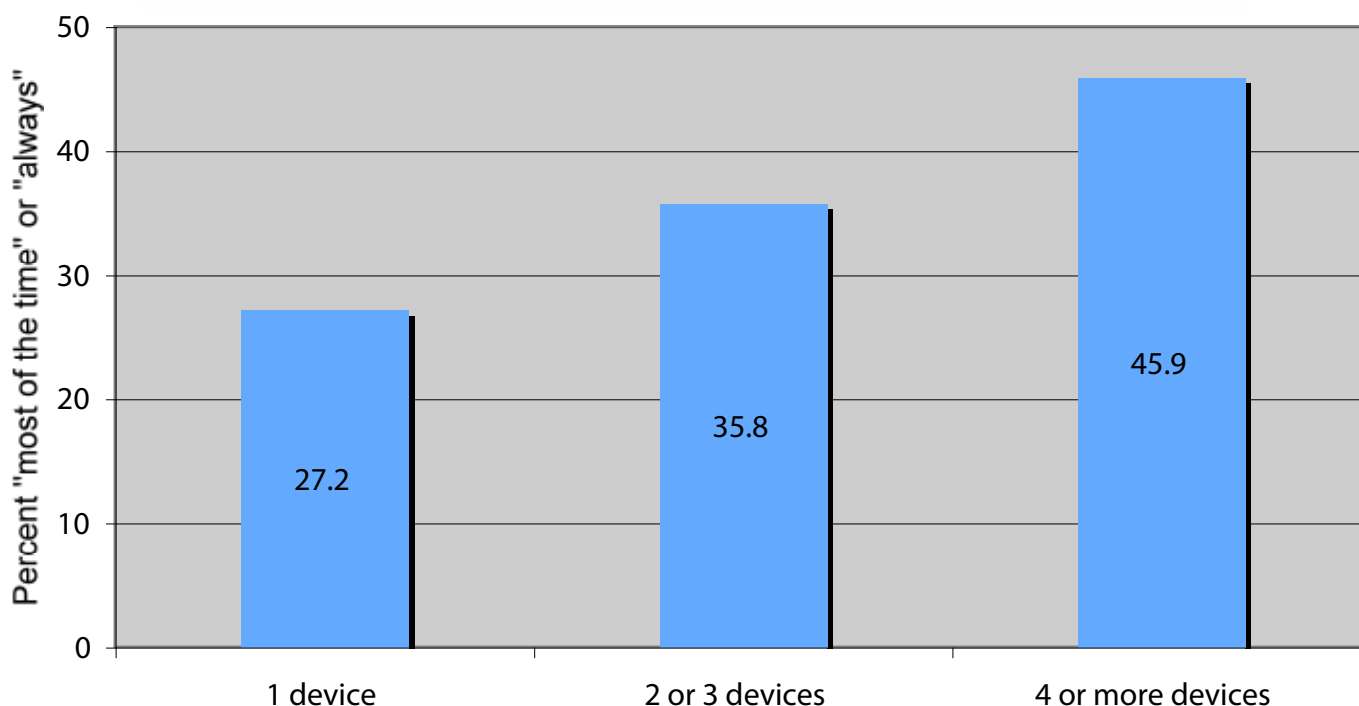




## Extent of AT usage and social isolation

The more AT a person uses, the more likely that their AT helps them cope with feelings of isolation. Only 27 percent of respondents who used a single AT device reported that their AT usually helped them cope with social isolation (“most of the time” or “always”), compared to 36 percent of those using 2 or 3 devices and 46 percent of those using 4 or more devices. Thus, it is not only the use of any technology that benefits people in reducing their social isolation, but also the extent of their AT usage.

**Proportion of AT users whose AT usually helps cope with isolation, by number of devices used**



## Conclusions

California Independent Living Center consumers with disabilities are highly satisfied with the assistive technology they use. Although the repair process can be problematic and there are concerns about costs, selection, and support services received, people tend to be particularly happy with the way their device functions. Fairly high levels of satisfaction hold true across disability groups, although people with sensory, mobility, or speech impairments tend to be a little happier than those with cognitive or mental health disabilities. Satisfaction levels were about the same regardless of who paid for the equipment, but the most impoverished respondents were somewhat less satisfied than wealthier respondents.

Scooters, ventilators, and adapted telephones get the highest overall satisfaction ratings, while hearing aids and computers get the lowest. Respondents tended to be less than satisfied with the repair process and costs of adapted vehicles, the repair process of electric wheelchairs, repairs and costs for computers, repairs and costs for specialized software, and the cost of hearing aids. By and large, however, a majority of respondents expressed satisfaction with most aspects of most of the more common AT devices.

People use their AT for all sorts of activities, including caring for themselves, getting around at home and in the community, reading and writing, participating in social, community, and family activities, and working, going to school, and playing sports. Younger adults typically use their devices for a broader variety of activities, while elderly

adults tend to engage in a more limited set of routine, practical activities necessary to maintain their health or their home.

Respondents typically regarded devices that help them connect with the outside world (computer equipment, cars or vans, motorized mobility devices, and hearing aids) as the most valuable in enabling them to continue living independently. In fact, assistive technology plays a crucial role in reducing social isolation among the population we surveyed. A substantial level of social isolation was reported by people across disability types, especially among working-age respondents who were not employed. But people whose AT needs were fully met were much less likely to experience isolation than those with unmet needs, and the vast majority of AT users reported that their technology helps them cope with feelings of isolation. Indeed, the heaviest users of AT were the most likely to say that their technology helped alleviate their feelings of isolation.

These findings—generally high levels of satisfaction, a wide variety of both participatory and practical activities engaged in, and the crucial role of AT in promoting social integration and reducing isolation—highlight the tremendous extent to which technology users value the devices they use, and gain important benefits that enable them to lead fuller lives. People who lack needed technology, a problem highlighted in the previous chapter, are at an enormous disadvantage, as are people whose technology is inadequate to enable full participation in society. For example, an

elderly person who uses a cane, but lacks the power wheelchair he or she would need to regularly venture out of the home and into the community, is missing out on participatory activities that might enrich his or her life.

Full participation, economic self-sufficiency, and independent living are three of the four national disability policy goals expressed in the Americans with Disabilities Act. The findings presented in this chapter show the crucial importance of assistive technology in helping people with disabilities to achieve all of these goals; the next chapter further demonstrates the importance of AT in enabling people to work and thereby to achieve economic self-sufficiency. Limited access to and awareness of assistive technology of all forms—not merely “medically necessary” equipment provided by public programs—hinders many people with disabilities from leading the fully integrated lives that the authors of the ADA envisioned.

## *Chapter 6*

# **AT and Work: The Road to Independence**

For most of us, the key to making our own choices often comes with a job. Having the financial means to choose one's shelter, food, transportation and other items comes with a paycheck. In addition to this paycheck, and just as important, work can provide structure, social contact, self esteem and sense of contributing to the greater good. We believe it is critical for people with disabilities to have the opportunity to work. And most people with disabilities want to work. However, the tools to get to work, perform the duties of the job and participate in social interactions are critical for successful employment.

In this chapter we will talk about how many of our respondents are employed, how many respondents use AT on the job, what types of AT equipment, accessibility and services they use and how it helps them. What AT would be most helpful in getting or keeping a job? Does AT provide a benefit and, if so, what are those benefits? We will examine what happens when an employee requests an accommodation from their employer and who pays for equipment on the job. Finally, we will look the very interesting and overwhelming response to the question, "What limits you most from working to your fullest ability?"

## Employment rate by type of disability

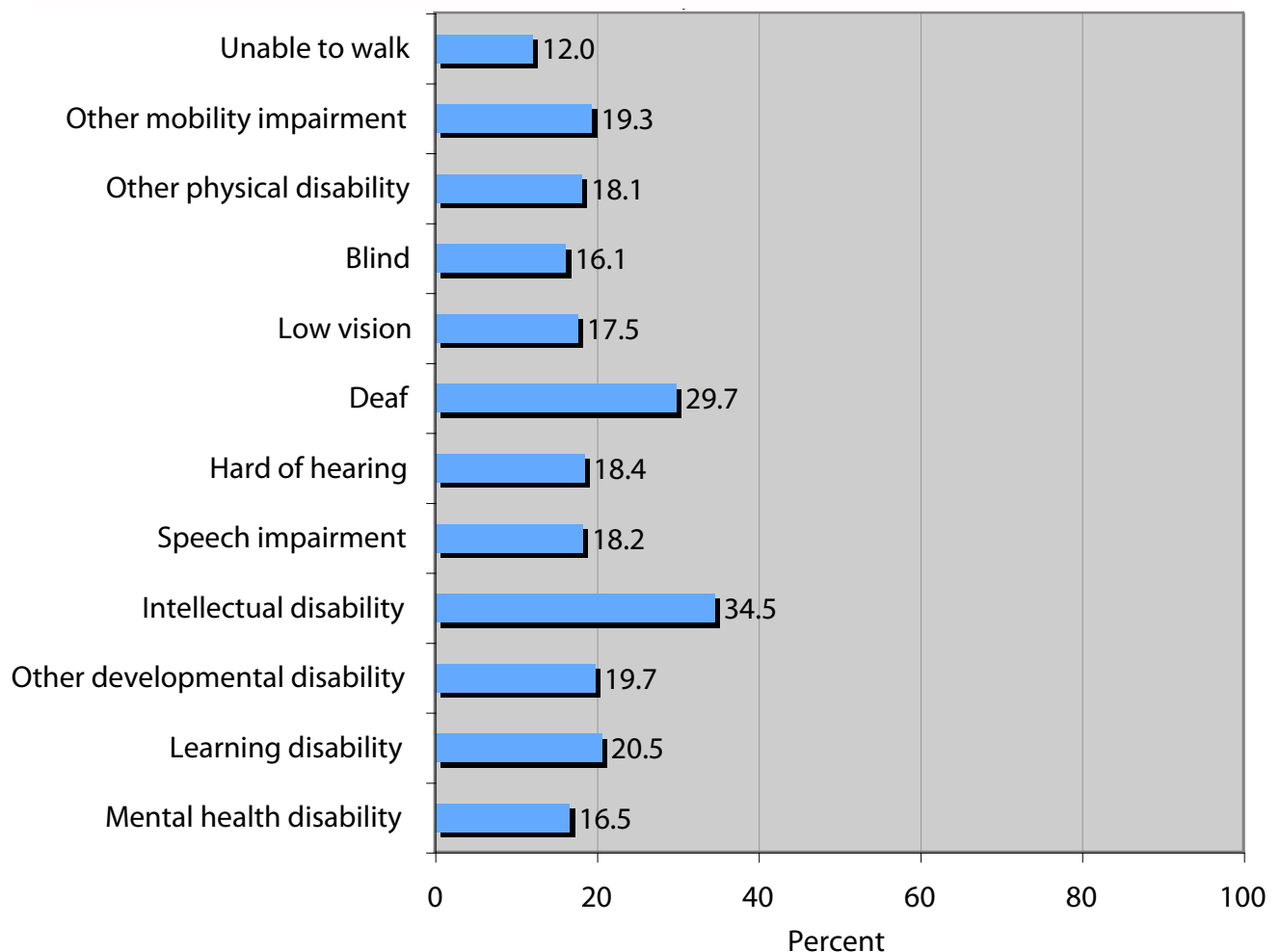
Of the 1,507 working-age adults who responded to the survey, 307 or 20 percent were actually working, whether at full-time or part-time jobs or in self-employment. But, as the reader will see, the impact of AT on those who are working is profound.

Only 6 percent of working-age respondents had full-time jobs. Some 10 percent had part-time jobs and 4 percent were self-employed. Interestingly, 24 percent of those who were working indicated that they were not working as many hours as they would like.

Looking at the employment rate of our respondents according to what type of disability they had, we see that those who are unable to walk have the **lowest** rate of employment at 12 percent. With all of the various mobility aids and the increase in environmental accessibility, it is discouraging to see this statistic. Those who are blind (16 percent) and those with mental health disabilities (17 percent) are also among the lowest.

People with intellectual disabilities have the **highest** rate of employment at 35 percent.

**Employment rate among working-age respondents, by type of disability**



Given that the Developmental Disabilities system invests heavily in employment supports, it seems to be paying off. While the employment rate of working-age individuals who are deaf appears to be high in the chart below, there are not enough of these individuals in our study to draw meaningful conclusions about employment among this population.

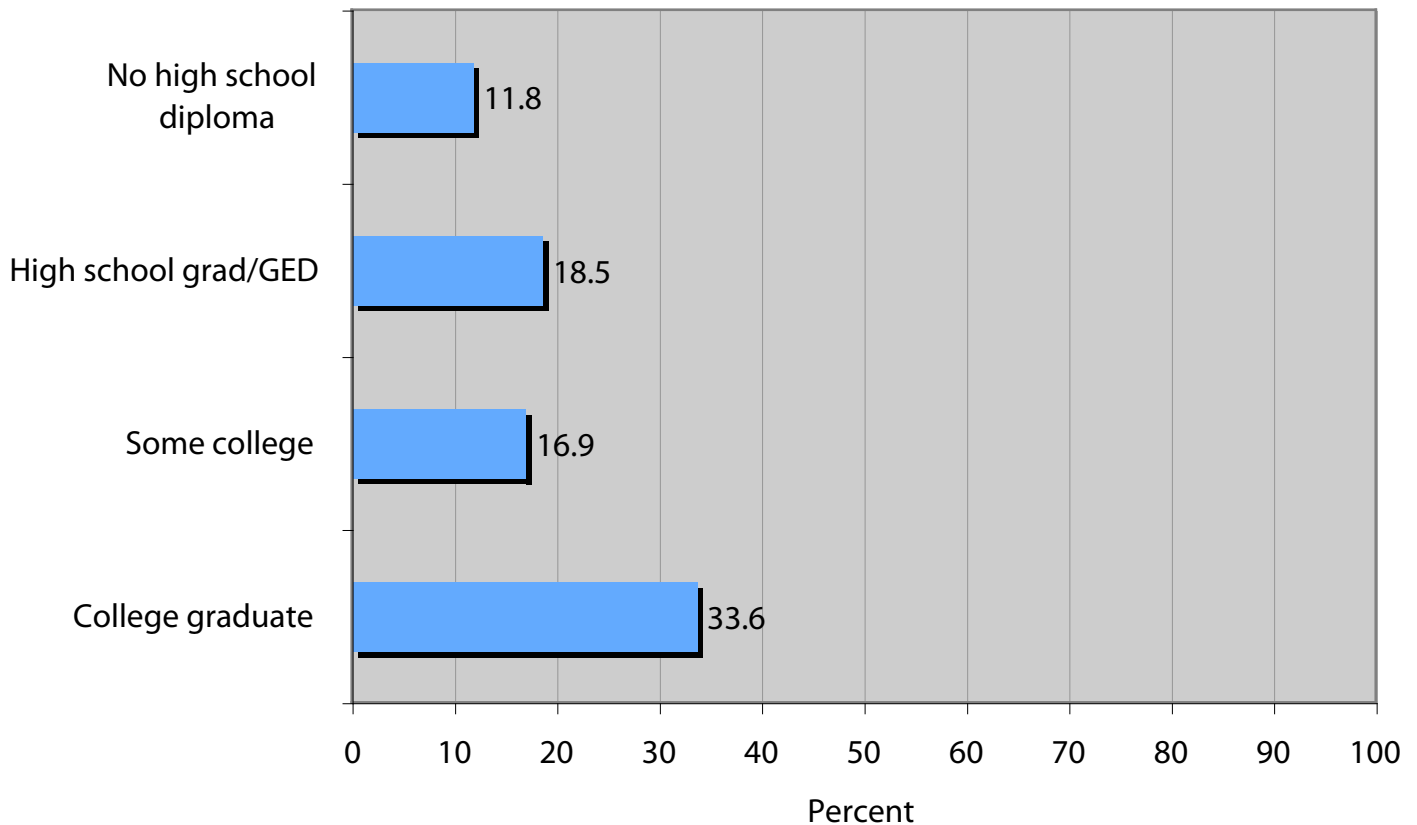
## Employment rate by educational attainment

When we looked at employment according to how much education people had, it became very clear that the more education one received the more likely one was to be working.

College graduates were three times as likely as people without high school diplomas

to be employed. College graduates were employed at a rate of 34 percent while those who had no high school diploma were employed at a rate of 12 percent. High school grads and those with some college were employed at a rate in between those with a college degree and those without a high school diploma.

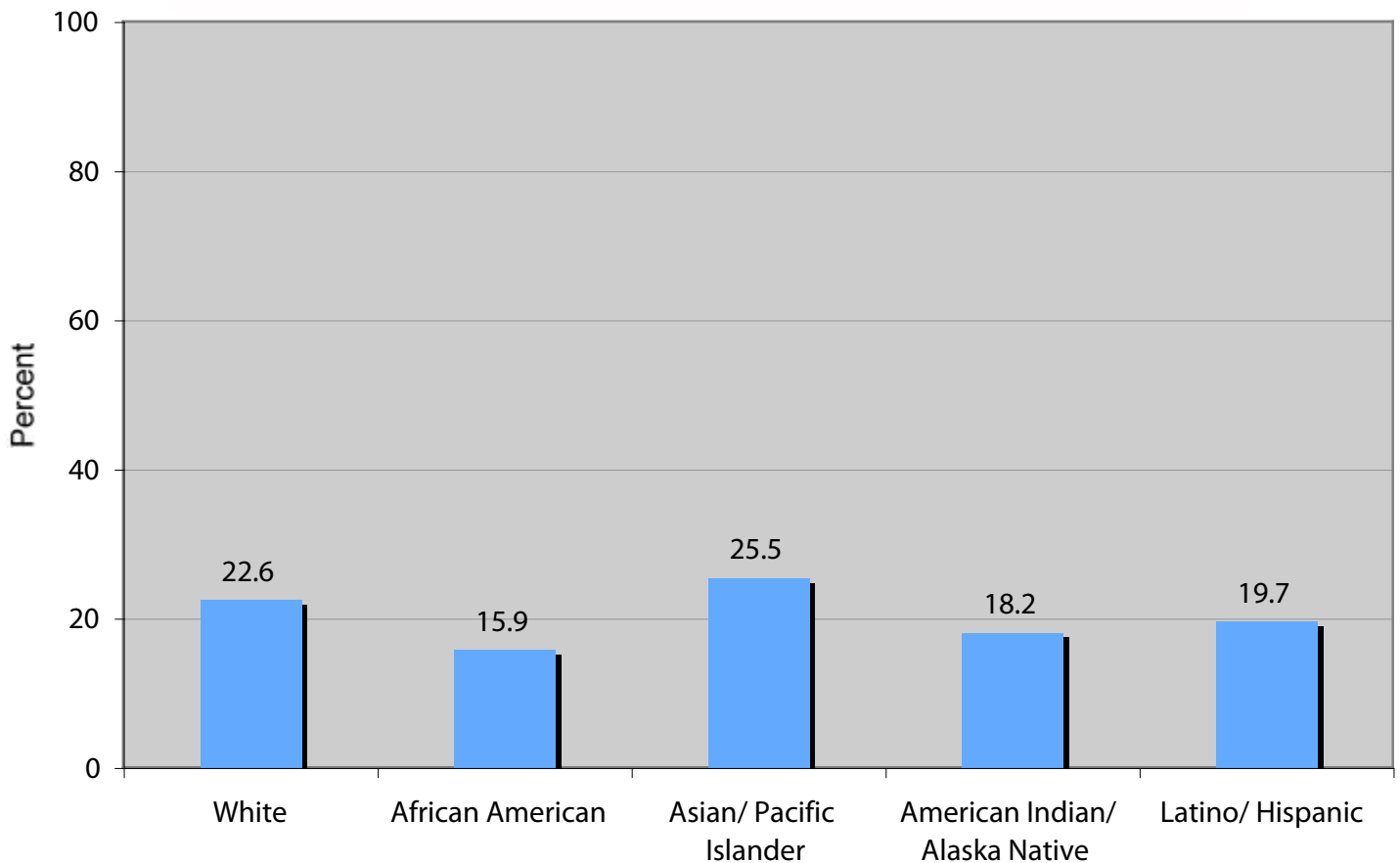
**Employment rate among working-age respondents, by educational attainment**



## Employment rate by race and ethnicity

Among working-age respondents, whites were significantly more likely to have jobs than were African Americans (23 versus 16 percent). Due in part to small sample sizes, no other racial groups had employment rates that were significantly different from whites, with Asians and Pacific Islanders at 26 percent and American Indians at 18 percent. Some 20 percent of working-age Latinos had jobs, not significantly different from non-Latinos in the sample (23 percent employed).

**Employment rate among working-age respondents, by race/ethnicity**





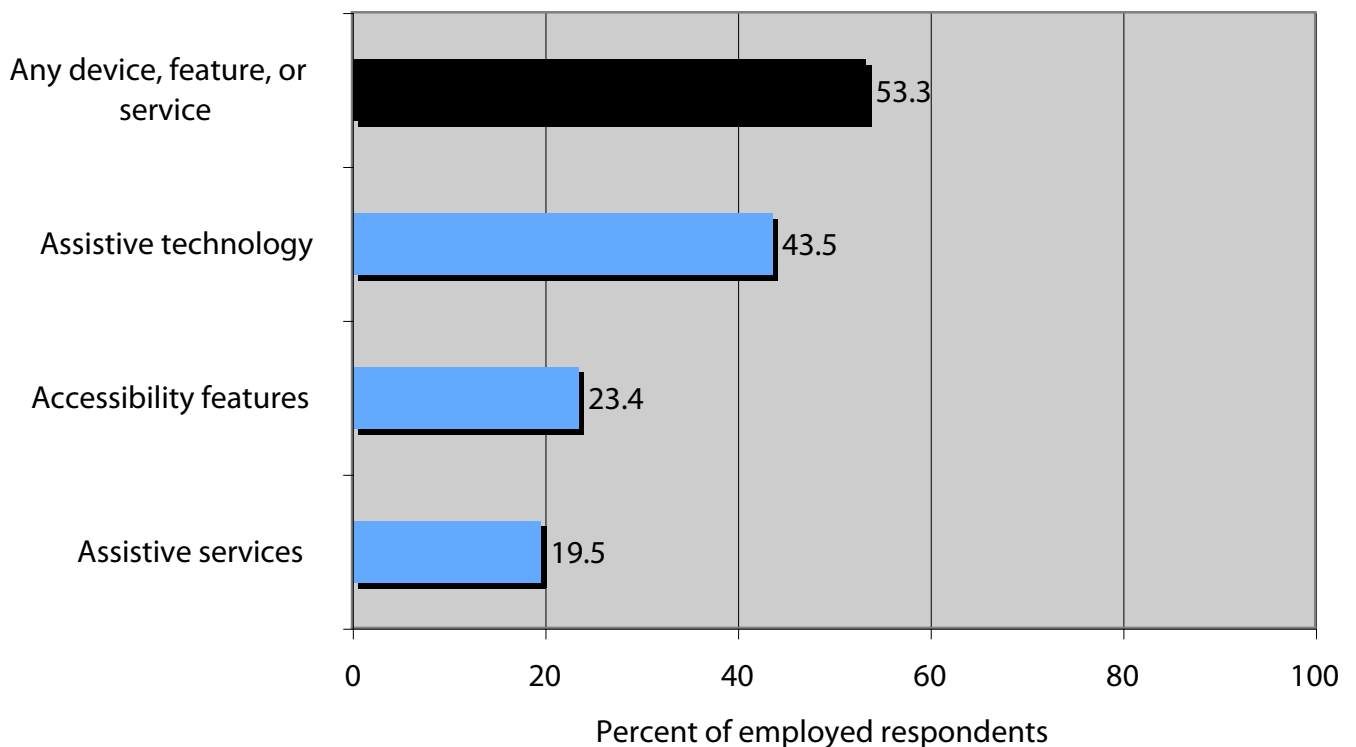
## Equipment, access features and assistive services on the job

When asked to check off all equipment, access features and services they used, 53 percent of our respondents indicated that they used one or more of these on the job. A list of choices (generated from focus groups and two pilot surveys) was offered, as well as space for writing in additional responses. We grouped the responses into three categories for ease of displaying and discussing them. The chart following this one will list the specific equipment, features and services actually used by our respondents.

The first category, **assistive technology**, included devices such as headsets, computers, wheelchairs, and reachers. Some 44 percent of our working respondents indicated that they used devices on the job.

The second category, **accessibility features**—as in access features in the environment—included ramps, automatic doors, ergonomic desks and chairs, accessible bathrooms, etc. Some 24 percent indicated that they used these types of accommodations on the job. The last category was named **assistive services** because these services (sign language interpreter, reader, job coaching) are provided to assist in the completion of a job task. A much lower percentage (20) reported using these services, which makes us wonder whether employers were reluctant to offer them, whether employees were afraid to ask for them, or whether relatively few employees needed such services.

**Use of AT, accessibility, and assistive services to perform work duties**



**Usage of assistive technology, accessibility features, and assistive services to perform job duties among employed respondents, by disability type**

	All respondents	Mobility impairment	Visual impairment	Hearing impairment	Cognitive impairment	Mental health disability
<i>Percent using technology, feature, or service</i>						
<b>Assistive technology</b>						
Telephone headset	14.6	19.5	15.8	11.8	8.3	9.6
Wheelchair	13.0	31.4	0.0	5.9	10.7	2.4
Magnifier	9.4	8.5	31.6	11.8	4.8	9.6
Adapted computer screen	9.1	10.2	17.5	9.8	9.5	12.0
Tape recorder	7.8	6.8	17.5	7.8	10.7	8.4
Voice activated software	6.8	10.2	12.3	7.8	7.1	3.6
Adapted keyboard	6.2	7.6	7.0	7.8	6.0	7.2
Wrist splints	5.8	10.2	10.5	9.8	2.4	4.8
Adapted mouse	5.8	10.2	3.5	3.9	3.6	3.6
Screen reader	4.5	3.4	17.5	7.8	6.0	3.6
Hearing aid/amplification device	4.2	3.4	5.3	25.5	2.4	4.8
Amplified telephone	3.6	5.1	10.5	15.7	2.4	4.8
TTY/pager/text communicator	1.0	0.0	0.0	5.9	0.0	0.0
Braille output device	0.3	0.0	1.8	2.0	1.2	0.0
Mouth stick	0.0	0.0	0.0	0.0	0.0	0.0
<b>Accessibility features</b>						
Ramps	13.3	29.7	5.3	5.9	9.5	6.0
Automatic doors	10.7	22.9	5.3	3.9	9.5	7.2
Ergonomic table/chair	10.1	16.1	12.3	9.8	7.1	9.6
<b>Services</b>						
Job coach	8.1	5.1	12.3	9.8	13.1	19.3
Assistant	5.5	9.3	1.8	2.0	4.8	6.0
Personal assistance services	4.5	9.3	0.0	0.0	2.4	2.4
Readers	2.3	0.8	8.8	2.0	2.4	0.0
Interpreters	1.9	1.7	3.5	5.9	3.6	4.8
Service animal	1.9	2.5	0.0	2.0	2.4	2.4

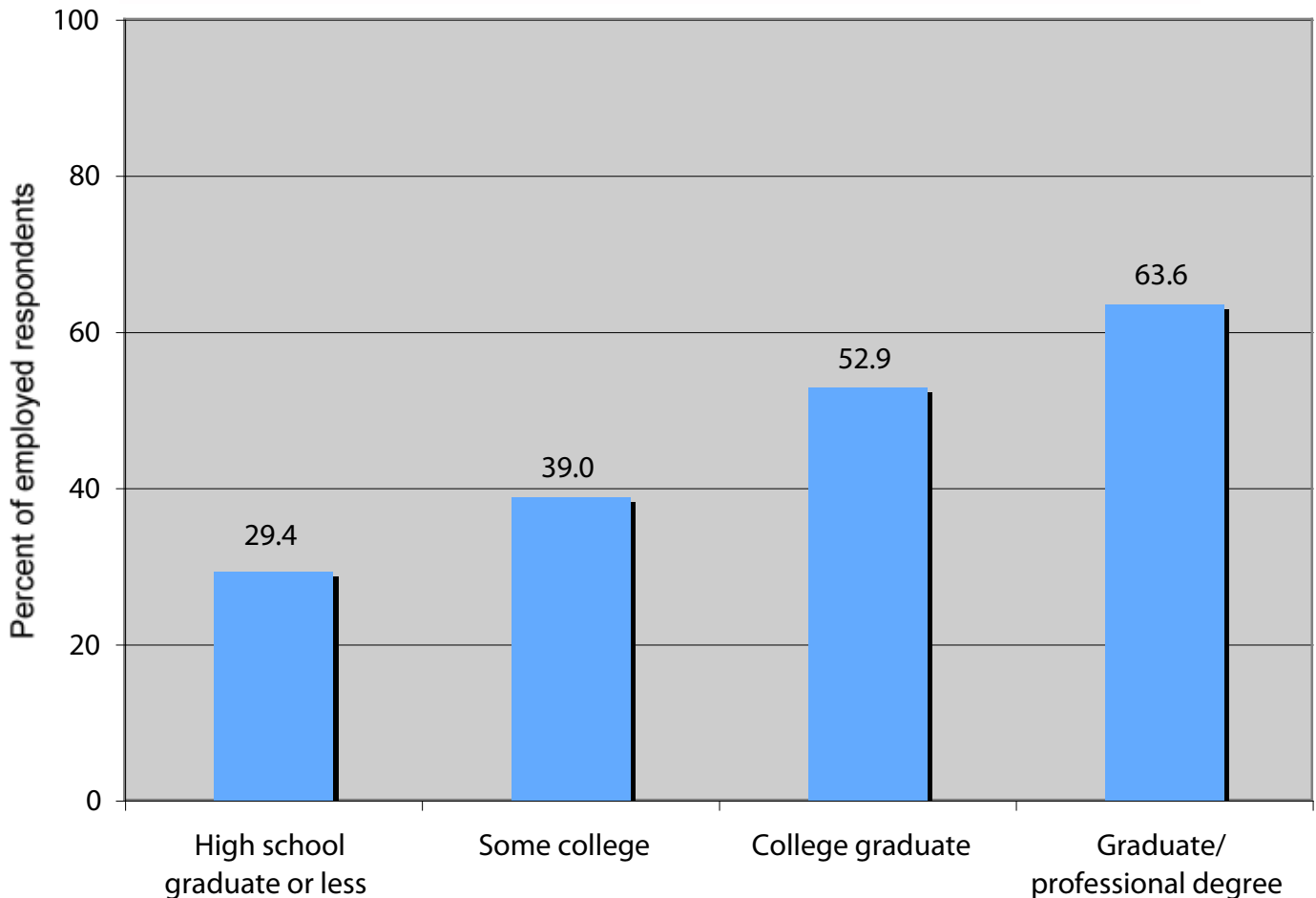
The most frequently mentioned device was a telephone headset (15 percent) and the least mentioned was Braille output device (less than 1 percent). Other devices to note include wheelchairs at 13 percent, adapted computer screen (9 percent), screen readers

(5 percent), hearing aids/amplified devices (4 percent) and TTY/pager/text communicators (1 percent). Note that many of the more widely used devices used to perform work duties are not particularly costly.

## Does educational attainment impact AT usage on the job?

Looking at only employed respondents, we wondered if there was a difference in using AT among those with different levels of education. Indeed, the use of AT on the job increases dramatically with educational attainment. The percentage of respondents with a high school diploma or less who are using AT on the job is 29 percent. That percentage more than doubles when looking at those with a graduate or professional degree (64 percent). The more education one has, the more likely one is to use AT to perform work duties.

**Use of AT to perform work duties, by educational attainment**



## The most helpful devices

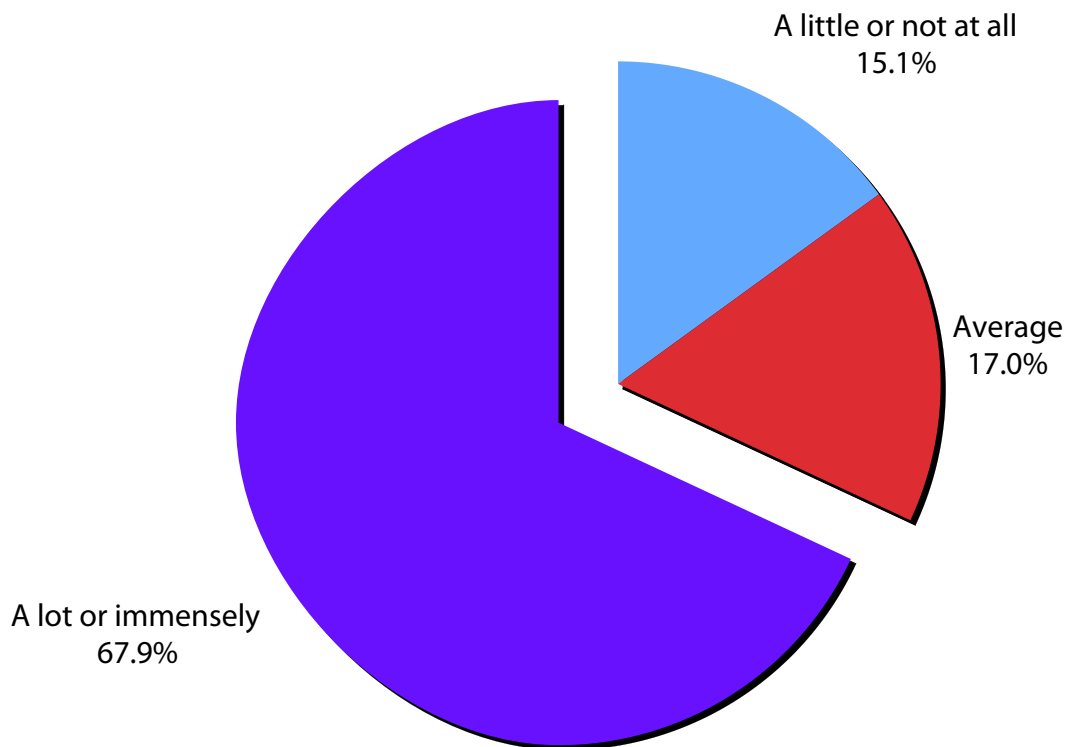
We asked respondents what AT devices and/or services would be the most helpful in getting or keeping a job. The list of devices most often mentioned is not surprising. Computers and Internet technology, so important to all of us for managing our lives and work, was first for 22 percent of those responding to this question. Wheeled mobility equipment was second at 15 percent. Transportation equipment (adapted or not) was cited by 13 percent of respondents. Items or services that were mentioned by less than 10 percent of respondents included additional job skills, ergonomic furniture, medical devices (braces, for example) and adapted phones or cell phones. For some respondents, a modest investment in technology or training could make a big difference in their employability.

<b>Devices mentioned as most helpful to getting or keeping a job</b>	
	Percent
Regular computer, accessories, laptop, PDA, Internet	21.9
Manual or electric wheelchair or scooter	14.9
Adapted computer or special computer software/hardware	14.5
Regular or adapted car or van, or equipment for vehicle	13.3
Additional job skills, training, or education	8.0
Ergonomic chair or other office furniture	7.6
Medical device (incl. brace or prosthesis) or treatment	7.2
Adapted phone or a cell phone	5.1

## Benefits of AT on the job

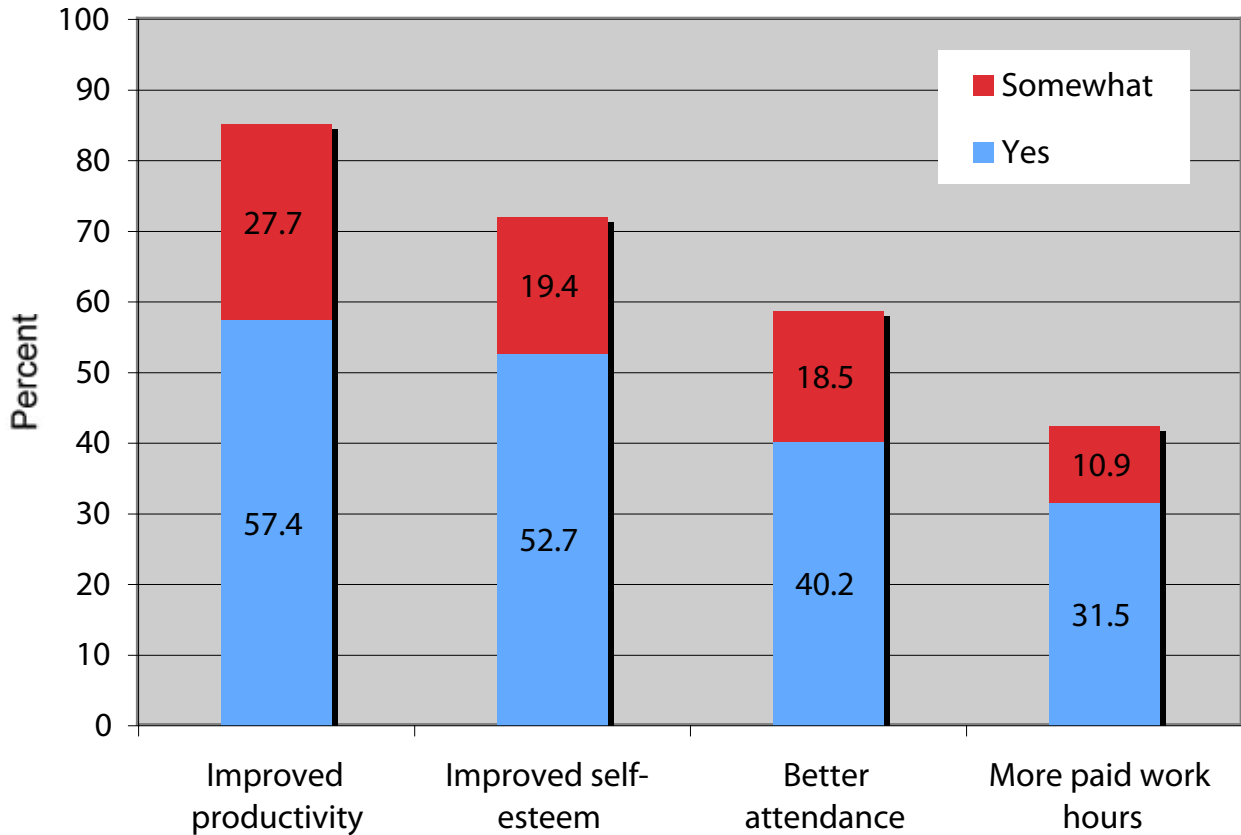
When asked if AT was helpful on the job, 68 percent of those who were working indicated that AT helped them “a lot or immensely” while 15 percent said “a little or not at all.”

**Extent to which AT helps at work**



When we asked what the benefits were to having AT on the job, respondents were quite specific. Combining the somewhat and yes response categories, we see that 85 percent cited improved productivity, which was the top benefit. Some 72 percent cited improved self-esteem; while 59 percent indicated that better attendance resulted with AT and 42 percent said they had more paid work hours. Clearly, having AT devices on the job provided a huge benefit to our

### Specific benefits of AT usage at work, among respondents using AT at work



respondents who worked. This is a finding that employers should find helpful—providing AT on the job benefits the bottom line in terms of productivity!

For service providers who help people with disabilities go to work, focusing more on AT will provide practical and emotional benefits that increase the consumer's chances of successful employment.

## Who pays for workplace AT?

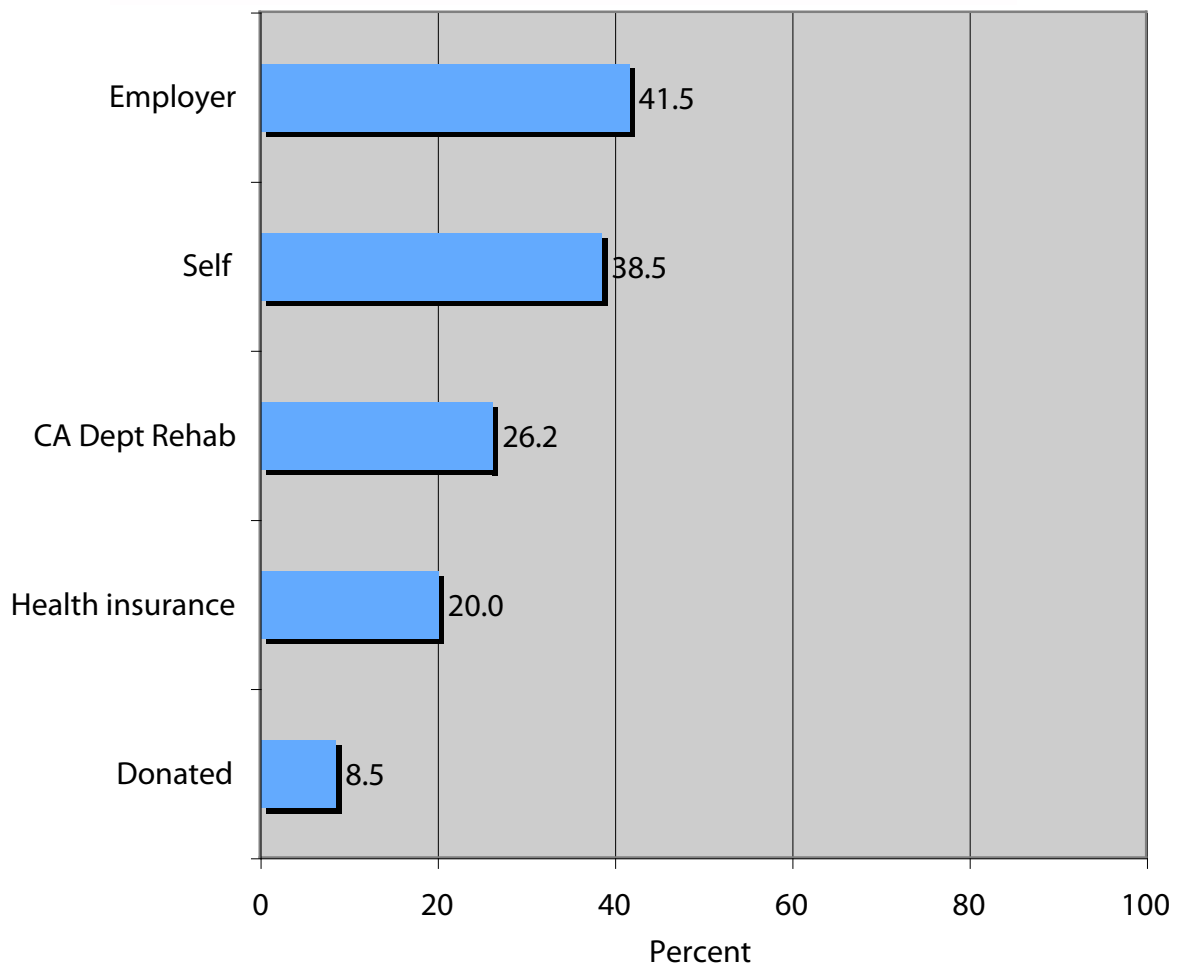
The top purchaser of workplace AT among our respondents was the employer (42 percent). The second largest purchaser was the employee (39 percent) and the Department of Rehabilitation was the source for 26 percent of the AT our respondents used.

The Americans with Disabilities Act puts the responsibility for reasonable accommodations on the job on employers, so it is not a surprise to see them as the top source. The downside to this is that employees with disabilities usually cannot take the employer-purchased equipment with them when they

change jobs. Thus, it can make it difficult to build a career by changing jobs and employers, if one has to face asking for the accommodation all over again.

It is surprising to see that, once again, consumers themselves are obtaining their own AT, even with the low level of income they receive. Further, DOR does not seem to be funding much of the AT for this group, which is puzzling given that they are federally mandated to provide equipment to assist people to get and hold a job.

**Sources of workplace assistive technology**



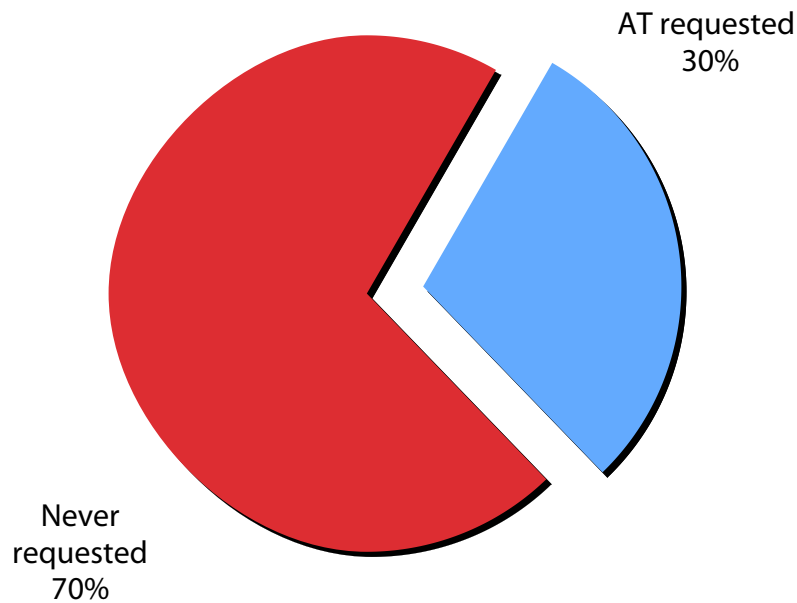
## Asking for reasonable accommodations on the job

We asked the working respondents if they had requested workplace AT from their employers and what happened when they did so.

Out of the 307 working respondents, only 30 percent or 92 individuals actually requested AT as an accommodation from their employers. Did the others not want to draw attention to their disability? Was the work

environment and/or management hostile to such requests? Were employees with disabilities unaware of employers' obligations to make reasonable accommodations and of successful strategies to request them? The area of reasonable accommodations is one that needs more in-depth research. Employers are a potential source of funding for work AT that should be utilized, as appropriate.

### Ever requested AT as a job accommodation





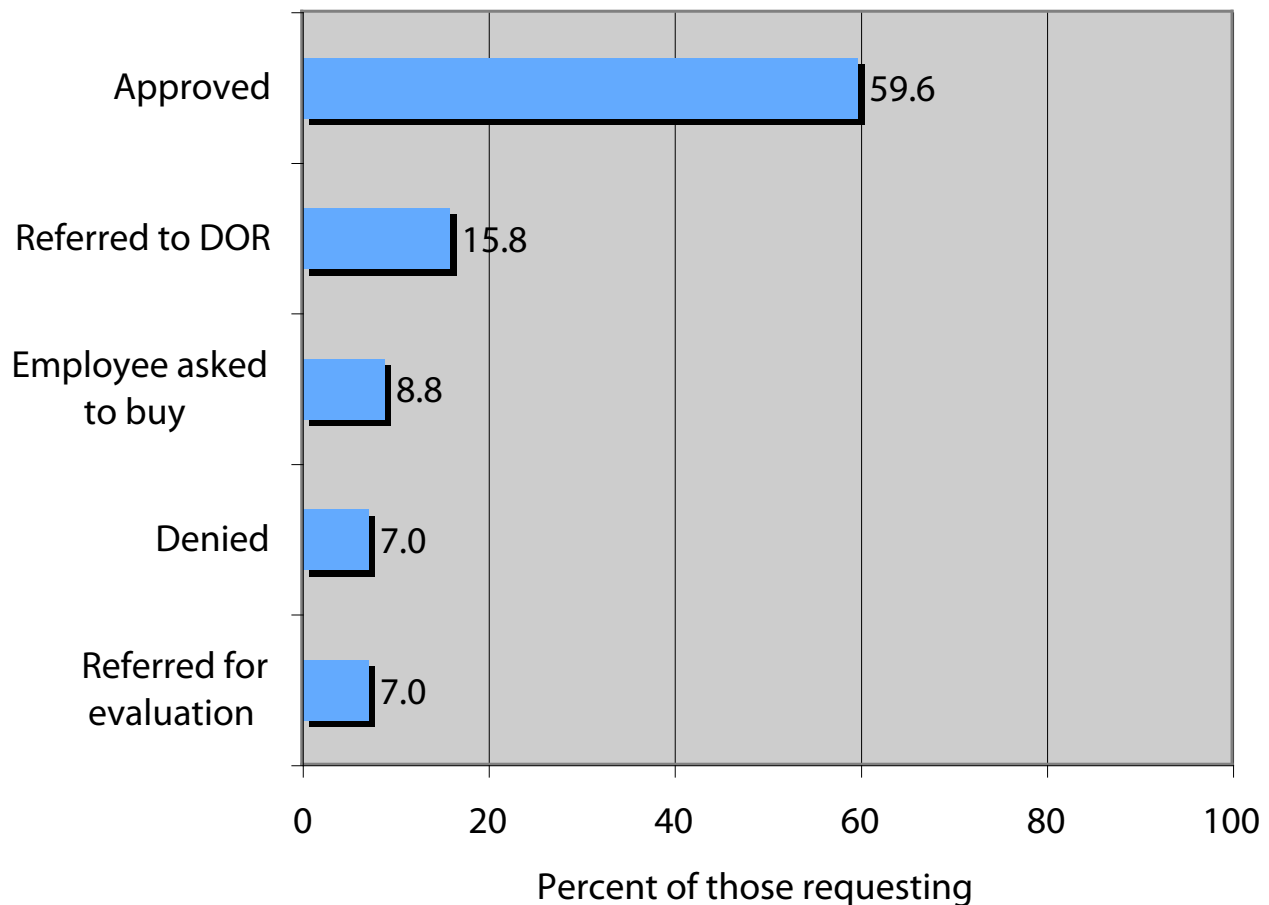
## What happened to those who requested reasonable accommodations?

Fully 60 percent got their requests approved! In addition, 16 percent were referred to the DOR. Unfortunately 9 percent were asked to buy their own equipment while 7 percent were referred for evaluation. Only 7 percent were denied outright.

The high success rate might be a good sign for others who want to make a request, but are fearful of the outcomes. On the

other hand, if the only employees requesting accommodations are those working in accommodating environments, then this rate of success may not generalize to other workers whose employers are less receptive. Research on what made requests successful would be helpful for consumers and employers to help them navigate this discussion more successfully.

**Outcome of request for AT as a job accommodation**



## Barriers to work

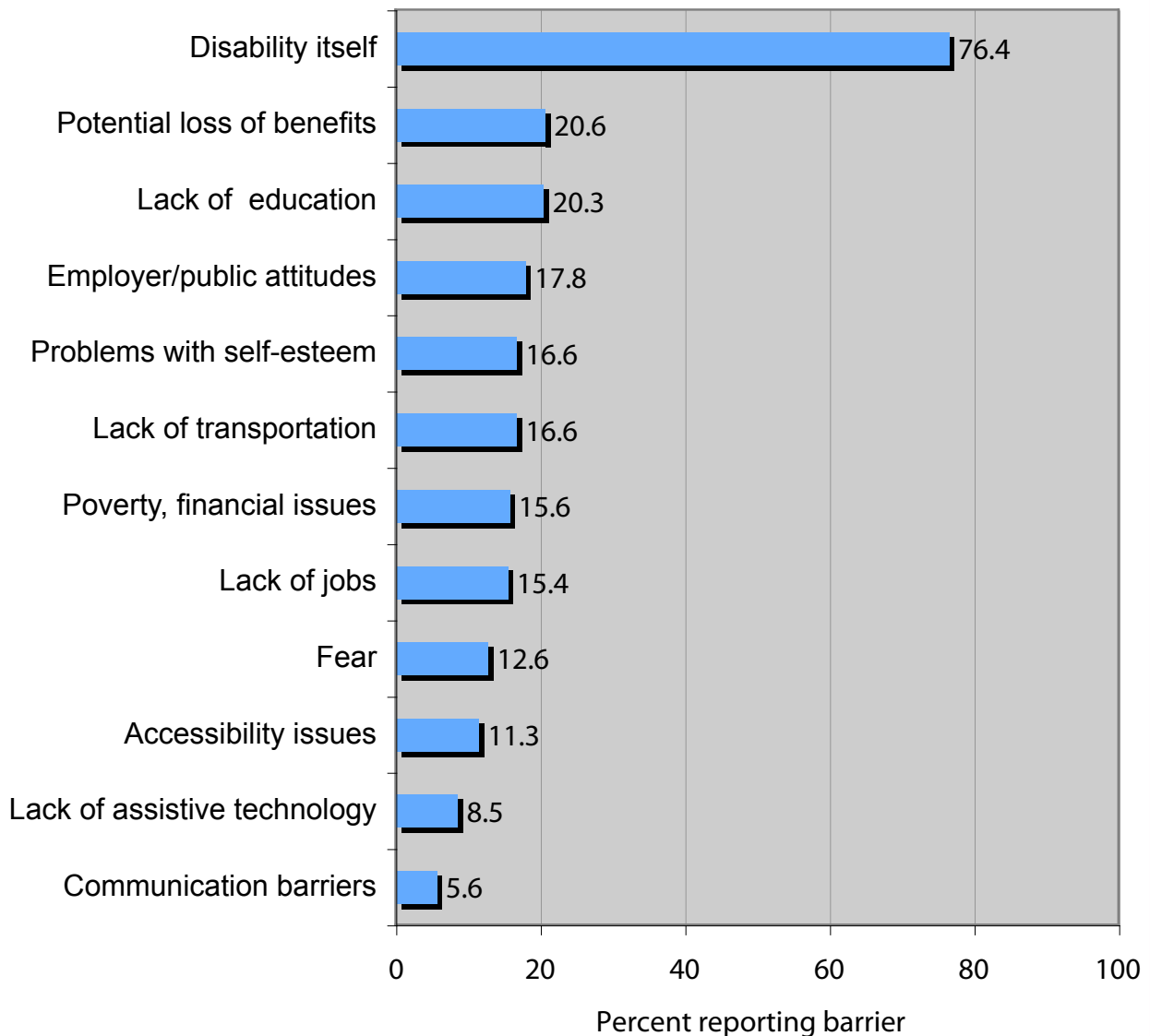
All respondents, not just those who were working, were asked to “**choose what MOST limits you from working** to your fullest ability.” We were astounded at the response. Thirteen response options (including space to write in a response) were listed to choose from and respondents were asked to identify the top 3 reasons.

Fully 76 percent responded that their disability was a major barrier. Every other barrier

—loss of benefits (21 percent), lack of transportation (17 percent) or jobs (15 percent), accessibility issues (11 percent), even lack of AT (9 percent) was cited significantly less than “my disability” (76 percent).

This is astounding in a state that has a long history of working to address most of these issues. For example, California has a work incentive program in place to help prevent the loss of benefits. But here we learn that a

**Perceived barriers to achieving full employment potential**



huge number of Independent Living Center consumers feel they can't work or don't see themselves as able to work. Looking at the respondents by disability does not reveal large numbers of so severely disabled individuals who could not work given accommodations or other assistance. In other words, we find it hard to believe that the vast majority of our respondents had limitations so severe that they truly could not work. Clearly we must continue and even increase the ways to communicate with people with disabilities that they can work; that it is critical to their independence and self esteem.

## Conclusions

Out of 1,507 respondents with disabilities of working age, only 20 percent or 307 were actually working. This mirrors the dismal national employment statistics and certainly indicates that we need to continue to work on the goal of employment. However, one sure solution is education, as those in our study who had the most education were three times as likely to be working as those who had the least education.

Among our respondents those least likely to be working were those with more severe mobility impairments and those who are blind or who have a learning disability. Most likely to be working were those who had an intellectual disability. The Developmental Disabilities system has put significant resources into supporting employment for their consumers.

A majority of working respondents reported that they used AT, accessibility features, or assistive services on the job. People with mobility or sensory disabilities were most likely to use workplace AT, as were those with more education. Those less likely to use AT on the job include people with mental health or cognitive disabilities and those with a high school diploma or less.

Most respondents who used AT on the job found it helpful. Significant benefits included increased productivity (84 percent) and increased self-esteem (72 percent). Increased productivity is a benefit that accrues to the employer, who should be motivated to support reasonable requests for equipment that increases the business's bottom line. Increased self-esteem is the

benefit that pays dividends to the employee personally. Other benefits include less absenteeism and more paid hours at work.

Every employer and every entity that works to help people with disabilities get jobs must make AT a big part of the process to achieve that goal. Only 30 percent of employed respondents asked their employer for accommodations and, of those, 60 percent were approved and another 16 percent referred to the Department of Rehabilitation for services. Knowing more about what makes a successful accommodation request will be helpful to others who are considering making a request.

Employers would do well to create a transparent and comfortable process for the employee to identify and request tools needed to make him or her more productive on the job. This should be standard operating procedure for all employees, not just those with disabilities. Employment service providers must value the impact that AT has on the individual with a disability and not be fearful of the cost. Getting evaluations to determine the right equipment, purchasing it in a timely manner and providing training, if needed, is critical to making people with disabilities employable.

The primary source of payment for workplace AT was employers (42 percent), and employees with disabilities were second (39 percent). The Department of Rehabilitation funded 26 percent. While it is the responsibility of the employer to provide reasonable accommodations, the employee usually does not get to take employer-provided

equipment on to the next job unless it is within the same company. Equipment funded by DOR and private insurance becomes the property of the individual with a disability.

We need to make it easier for consumers to take that equipment along with them, perhaps through a tax credit for the cost of workplace AT. Less likely, but intriguing, would be to create a government sponsored workplace AT equipment center whereby those with disabilities could get the equipment they needed. If appropriate, it could be recycled when the employee left the job or the workplace.

The most revealing information to come from this section of the survey revolves around primary barriers to working. While we would like to think that the lack of AT is a primary barrier, it is not. Not yet. The primary barrier is “my disability” according to 76 percent of the working-aged respondents. Other barriers, such as loss of benefits, transportation, employers’ attitudes, and access to buildings, were each reported by 21 percent or less of the respondents. We believe that the attitude the person with a disability holds about his/her disability is the key to employment. Society has long promoted a charitable view of people with disabilities—let the government or family take care of that person. Unfortunately, people with disabilities themselves seem to have “bought into” this notion. One has to believe one can work and have gone out to look before encountering the other barriers we know exist.

If contemporary U.S. policy is sincere about expecting people with disabilities to go to

work, then much more effort needs to go into showing them that they can. The Social Security Advisory Board’s September 2006 report, *A Disability System for the 21<sup>st</sup> Century*, does a terrific job outlining the problems with our current benefits system. In its current form, the system limits the options for people with disabilities to be self-sufficient yet able to receive benefits as needed, based on current functional limitations and any future changes that might occur. The report also puts forth a vision for change that is breathtaking. One of many striking statements made by the report addresses what our respondents might be telling us about their disability being the top barrier to work.

*“The process {of seeking benefits} tends to make an individual who might have been able to work at an earlier point in time less and less capable of doing so. Attachment to an employer, the maintenance and improvement of skills, the sense of belonging to the workforce, **the mindset that work is possible—the loss of all these factors, combined with the passage of time and with the program requirements that reward inability to work**, conspire to transform a person from an “impaired individual” with potential into an individual who, in fact, has come to meet the definition “unable to work.” (pg. 8, emphasis added)*

This does not have to happen. Starting with what the Social Security Advisory Board calls a “fundamental cultural shift away from a presumption that work was out of the question and toward a presumption that recipients did have the ability to work,” (pg. 8) we call upon education, government and

non-profit entities to hold an expectation that people can work and to help the individual live up to that expectation. Those entities should “paint a picture” of how people with a wide variety of functional limitations could work. Raising public awareness through long-term media campaigns, connecting working mentors with disabilities to those who are wondering about work and transforming long-term disability benefits into long-term employment benefits are sorely needed steps in the right direction.

Such a cultural shift and activities to support it must happen from day one of disability onset, whether it be in the mind of a parent with a newborn who has a disability or in that of an individual acquiring a disability at any age. Individuals with disabilities, their families and friends, potential employers, the disability benefits system, and society as a whole must be made to abandon the outmoded notion that functional limitations *per se*, in the absence of serious health complications, in any way preclude a lifetime of productive employment and economic self-sufficiency. People with disabilities need not only increased employment opportunities, but also the belief in their own ability to work, the social and practical support needed to be successful in the workforce, and the societal expectation that disability itself is no barrier to full participation in economic life.

## Chapter 7

# Vision of a Perfect AT System

Over the past 3-4 years, there has been a series of TV commercials featuring famous people saying something wise under the unifying marketing theme of “The more you know...” The more you know the better your life will be, the happier and so forth. That theme is fitting to unify a vision for the perfect AT system, for it really is all about “the more you know.”

The more people know—and by people we mean not only people with disabilities, but also their families, their healthcare providers, their teachers, their care providers and the general public—the better informed they are about how devices, services and architectural design can help enrich the lives of others, support everyone in using their talents and help prevent a person’s circumstances from being diminished. In other words, everyone must know about the value of AT and AT must become everyday equipment; it must become mainstream.

In the US, one of the ways that something becomes normal is through advertising. Let’s show devices in commercials, TV shows, movies and ads, so that consumers come in contact with equipment that can help them function better in their family and their community. The general public, including healthcare providers, service providers and employers, can then begin to see technology and barrier removal not in terms of stigma,

but as something that is desirable. It should be reassuring, as all of us face our own or our loved ones’ disability as we age, that the three-wheeled scooter, the accessible door to the grocery store or the captioning service on the evening news is there for us too. Let’s put this equipment for sale in mainstream stores such as Wal-Mart, Target and others where the vast majority of people shop.

The first part of the vision is all about empowering people with disabilities with the knowledge of what equipment is out there to help them live the life they want to live. Knowledge is power; with it comes options and possibilities for individuals and their families.

Then, as society and individuals with disabilities continue to change their view of disability from helplessness or dependency to competence with the right supports and tools, the issue of getting the right tools will take on new significance. There are examples everywhere of people with a wide variety of disabilities growing up, getting an education, choosing where and how to live, going to work, dating, getting married, raising children, engaging in recreational activities, and participating fully in the community. As people with disabilities seek assistance in “getting a life,” those who provide assistance, mentoring or information need to raise the issue of AT.

## The VISION

*Individuals who acquire disabilities, whether at birth, during childhood, adulthood or as a senior, will be made aware of technology that could help them, and asked about their need for equipment by a variety of medical and community service providers at key points in their relationship. Information specific to their need for devices will be offered, and evaluations for equipment will be available on a regular basis. Minority communities must not be left out when it comes to finding out about and getting AT; that is also true for certain disability groups such as those with cognitive or mental health disabilities. People with disabilities must be involved in the development of equipment and in making funding decisions. Funding for equipment needs to be readily available, as do opportunities for trying out equipment, for talking to others who use it, and for obtaining refurbished equipment from a recycling program, donated by people who no longer need it. Training and maintenance services will be offered and available, as well as upgrades and replacement. To do less than this means that individuals with disabilities will experience a loss of independence, diminished economic participation and increased social isolation at various times in their lives.*

The vision, piece by piece:

**Individuals who acquire disabilities, whether at birth, during childhood, adulthood or as a senior, will be made aware of technology that could help them, and asked about their need for equipment by a variety of medical and community service providers at key points in their relationship.**

Individuals with disabilities and their families should be able to get information about devices from their medical providers and from community service providers with whom they interact. Just as, currently, general healthcare providers and health and social service organizations serving minorities all stress healthy living practices such as not smoking or controlling one's weight, we need these same entities to work together to bring up the issue of assistive technology when working with an individual with a disability for the first time. "Are you aware of equipment that can help you function more easily? If not, there are some people, agencies, websites and literature that can help you." Sharing intake information across service providers right now poses serious privacy issues, but in the future, as those get resolved, a single intake that asks the usual health and living questions should also ask about the need for AT. Answering the same questions at each organization is aggravating, according to many in our focus groups.

The medical community, community-based organizations and government agencies are going to have to be educated about offering not only life-sustaining equipment, but also equipment that fosters independent living and community participation. At the very least, each group should have a focus and be able to refer to the others. For example, if the medical community is going to be responsible for life sustaining equipment (medical equipment such as ventilators, electric wheelchairs, implantable hearing aids, prostheses, pace makers, etc.), they also need to be able to connect their patients to other



organizations that can provide information about and access to computers, accessible telephones, adapted driving controls, home modifications, adapted eating utensils, etc. These are the types of IL and community participation tools that can help alleviate social isolation and dependency.

It is very important to include minority community agencies and channels for receiving and conveying information. For example, the Latino community has less contact with health care providers, so it is very important to make sure those community-based sources of information and services introduce the notion that there are tools that can help a person with a disability function more easily or more efficiently in their family and community.

Finally, this discussion of need for devices should occur as the individual grows physically or ages; their disability changes for better or worse, their activities change, or life changes occur. This is a discussion that occurs repeatedly over the life span of the individual.

**Information specific to their need for devices will be offered, and evaluations for equipment will be available on a regular basis. Minority communities must not be left out when it comes to finding out about and getting AT; that is also true for certain disability groups such as those with cognitive or mental health disabilities.**

Not everyone gets their information the same way, so different methods will be

important. While many survey respondents said they got information from their health care providers, they also indicated that the Internet, disability organizations and ads were used. Making information easy to find in many different contexts will be important. A sustained campaign about the existence of assistive technology and where to get information is needed. Today, nearly everyone knows that smoking is harmful to one's health—the same sort of techniques and commitment is needed to inform everyone that there are tools and devices to help people with disabilities live, work and play much like anyone else.

Good, easy to read and non-stigmatizing information, in the language used by that community, will be important. Also important is recognizing that not all cultures value or look at independence in the same way. The concept of “interdependence” is a much more inclusive term. What tools will help you contribute to the well-being of your self, family and community, given the functional limitations you experience? What will help you navigate your community in the manner most accepted?

Several communities and groups need to be mentioned specifically here. We know that African Americans and Latinos have less access to equipment. The same is true for people who are cognitively impaired and those with mental health issues. More research needs to be done to look specifically at these four groups. But we know that Latinos have less access to health care providers, who are often the primary source of information and, perhaps, referrals for equipment. The very low rate of equip-

ment usage among people with cognitive or mental health impairments suggests more equipment needs to be identified and shown as useful for these populations. It also suggests that getting information out to consumers with those disabilities, their families and support system will be important.

Consumers asked for stories about people using equipment. Learning about people with similar disabilities that use equipment to participate in community activities helps to demystify assistive technology. Peer-to-peer interaction about the possibilities of equipment, how it is used, how it can be paid for and what to look for provides a strong support system. Just like *Consumer Reports* helps one to make educated decisions about what to buy, peers who use devices to live independently, work, go to school, travel about the community, have a family and recreate are a very important resource in this system.

As one begins to consider using devices, it is critical to get quality, independent evaluations. These evaluations should be conducted by those who have no financial stake in which products are offered. This will help ensure that the consumer finds the best possible match, instead of being forced into a particular piece or brand of equipment because the evaluator gets a commission. Evaluations need to be affordable and easy to find. It is very important that the consumer play an active role in the evaluations and that his or her needs and concerns be addressed.

**People with disabilities must be involved in the development of equipment and in making funding decisions.**

Savvy companies who want to make sure they get the most out of their Research and Development programs often ask users for their opinion on a new product or service. Companies such as Cingular Wireless and AT&T have included cell phone users with disabilities in their advisory groups with great success. Hands-free cell phones often mean that you don't have to look at it to use it. What a boon to blind people who want that technology, great for people without the use of their arms or with limited mobility and good way to address the driving public's need to safely drive and use the telephone! Including people with a variety of disabilities will help companies serve new markets or old ones better.

Often with public and private insurance companies, the actual decision about purchasing equipment for people with disabilities is made by someone who does not have a disability. We think that is a recipe for disaster. Decisions not to purchase a good-quality wheelchair seating or positioning system can result in escalating healthcare cost later, for example. Funders will make better decisions about what equipment to purchase when the decisions are made by, or in consultation with, people with disabilities who understand the importance of possessing the right equipment.

**Funding for equipment needs to be readily available, as do opportunities for trying out equipment, for talking to others who use it, and for obtaining refurbished equipment from a recycling program, donated by people who no longer need it.**

Once one has identified the equipment one wants to use, finding and paying for it becomes the next barrier to remove. Many would like to try the equipment before buying it, so a dream piece of the perfect AT system would include ways to borrow the equipment and try it out in the environment in which it will be used—at home, in the office, at school or even in a recreational setting. If it works, then the resources to acquire that device will not be wasted.

Woven throughout the research we conducted over the past five years is the plea for more funding. More money is needed to provide assistive technology and it needs to be provided in a way that enables consumers to take the equipment with them, as well as allowing for necessary exchanges. These are all ways that help a person get the devices needed.

Schools won't allow children to take equipment home on the weekend or over the summer. Too many employers have adapted computers, work stations, telephones, etc., that no one uses because there might not be a person with a relevant disability on staff at that moment. Individuals with disabilities outgrow equipment, their disability changes or the individual dies leaving equipment that could be used by someone else. Refurbishing that equipment and matching it to

others who can use it is a key focus of the most recent re-authorization of the Assistive Technology Act, in 2004.

**Training and maintenance services will be offered and available, as well as upgrades and replacement.**

As all of us who drive know when buying a car it is critical to learn how to drive it properly and keep it maintained with periodic visits to the repair shop. Finding repair shops that have loaners is very important if we want to stay mobile while the car is in the shop.

All of this holds true for assistive technology. In the field of disability supports though, this arena is where safety, continued participation and even health gets compromised.

Too often, assistive technology is given to a consumer, particularly an adult, who gets very little training on how to use it. If the equipment is complex or hard to understand at first, the chances are it may be abandoned, wasting those resources. Having access to repeated training, to a family member or friend who has also been trained and to peers who use the same equipment can help the consumer to be successful with his or her devices.

Regular maintenance and even repairs are an important part of keeping one's tools in good shape. But having to stay in bed for a month or even six while waiting for the equipment to arrive or come back from repairs really makes it hard to "get a life" and keep it going. A network of shared equip-

ment banks and better repair facilities with loaners would be beneficial. Providing extra reimbursement for repair shops who loan out equipment might provide the incentive needed to make this work.

Replacement of devices is a bittersweet moment of change. What you have come to rely on and be comfortable with no longer works or fits and must be replaced when it is no longer useful. It is an exciting time to find out about the improvements that have been made to the equipment, but it may mean learning a new way of doing what you've always done.

Often insurers and public health programs have a rigid schedule of when devices can be replaced which can leave the consumer without equipment or using dilapidated and sometimes dangerous devices while waiting for the time period to elapse. AT funders should consider setting ranges of time between replacements of equipment so that there is flexibility.

**To do less than this means that individuals with disabilities will experience a loss of independence, diminished economic participation and increased social isolation at various times in their lives.**

Having a disability is becoming a natural part of life as the medical industry makes advancements that allow people to live longer. People who not too long ago would not have made it past infancy or childhood are living much longer due to improved medical care and the equipment and services available to support them. Just

as able-bodied people would not accept staying home from work for six months while their transportation was being fixed, neither can people with disabilities afford to wait because they lack the devices they need to "get a life and live it."

# Appendix A - Individual ILC Participation

Center	SENT					RETURNED	
	English	Spanish	Braille	Un-deliverable	Totals	Totals	Return Rate
CCCIL - Salinas	600	400	0	5	995	65	6.53
ILRC - San Francisco	1,000	0	0	30	970	188	19.38
TILI - Eureka	190	10	0	5	195	40	20.51
CID - Belmont	400	100	0	8	492	40	8.13
CIL - Berkeley	836	81	16	50	883	130	14.72
CIL - Fresno	539	200	0	41	698	93	13.32
DRAIL - Modesto	700	0	0	0	700	71	10.14
FREED - Grass Valley	985	15	0	30	970	134	13.81
ILRCCC - Concord	900	100	0	150	850	162	19.06
PIRS - Auburn	390	10	0	26	374	35	9.36
SVILC - San Jose	800	50	0	100	750	95	12.67
A2i - San Diego	750	250	0	200	800	131	16.38
CAC - Riverside	500	100	0	46	554	74	13.36
CRS - East L.A.	150	150	0	29	271	12	4.43
ILC - Claremont	400	0	0	0	400	73	18.25
ILCKC - Bakersfield	400	100	0	99	401	30	7.48
ILRC - Santa Barbara	680	20	19	37	682	83	12.17
Rolling Start - San Bernadino	459	104	0	40	523	78	14.91
SCRS - Downey	450	250	0	30	670	139	20.75
WCIL - West L.A.	950	50	0	100	900	203	22.56
	<b>12,079</b>	<b>1,990</b>	<b>16</b>	<b>1,026</b>	<b>13,059</b>	<b>1,878</b>	<b>14.38</b>

## Northern Region

# participating centers **11**  
 Distribution **7,877**  
 Returned **1,053**  
 Rate **13.37**

## Southern Region

# participating centers **9**  
 Distribution **5,201**  
 Returned **823**  
 Rate **15.82**

# Appendix B – Sample of Consumer Survey

*(This survey is now closed)*

Community Research for Assistive Technology – California AT & Consumers Survey



**Your Code # is:**

The California Foundation for Independent Living Centers (CFILC) is a group working to improve the lives of people with disabilities. Together with the University of California, San Francisco, the University of Northern Colorado, and California State University, Northridge, we are researching technology used to help people with disabilities in their daily lives. Assistive Technology is any device that a person with a disability uses to live or work more independently. It can be a computer, a walker, or even Velcro on a pen.

One way to collect a lot of information from a lot of people is to use a survey. Across California people with disabilities will be supported in completing a survey by phone, in writing, in alternate format or in person. This survey will collect information about your **Assistive Technology** use.

This survey is considered research. There are rules about protecting people and their rights when doing research. You may choose not to send in the survey or only answer some questions. You can call us at 1-800-390-2699 to ask us about the survey or if you need help filling it out.

Sending in the survey by mail or over the Internet means you are choosing to answer the survey. No benefit or service will be given or taken away if you answer the survey. We are collecting this information because we believe it will help people understand why Assistive Technology is important. Your responses are welcome. No one will know that you have participated. **Patricia Yeager is the Principal Investigator and can be reached by calling our office at 800-390-2699. Dr. Kenneth Galea'i, Research Support, can be reached at 970-351-1541.**

The survey will take between 30 and 40 minutes of your time. It might take longer if you are using a translator or interviewer. If you would like to take the survey online, please go to [www.atnet.org](http://www.atnet.org). The survey is also available in alternative formats by calling 800-390-2699.

To thank you for completing this survey, CFILC would like to send you a check for \$20.00. If you would like to receive this gift you will need to give us your name and address at the end of the survey. **IMPORTANT:** You may take this survey only ONE time, and only ONE check will be issued per person! You will receive your check from CFILC within 7 days of mailing. Checks will be mailed until monies run out. Once you have completed the survey, place the last page with your name and address in one of the postage-paid envelopes provided. Then, place the survey form in the other postage-paid envelope and mail both envelopes to CFILC.

For those answering the survey on the Internet: If you are unable to complete the survey in one session, please click on the “Finish Later” button at the bottom of the page. You will be given a Record Number and Password - **please write these down.** When you return to complete the survey, enter your Record Number and Password into the boxes at the beginning and continue filling out the survey where you left off.

The AT Network website ([www.atnet.org](http://www.atnet.org)) provides information about Assistive Technology and allows individuals to search online for devices and services. People can also receive information about Assistive Technology services and resources by calling the AT Network Information and Referral Service at (800) 390-2699 or through its TDD line at (800) 900-0706.

The Community Research for Assistive Technology project is looking at the use of AT in the lives of people with disabilities. Community disability leaders research AT in four main areas: employment, health, community inclusion and technology for function. For more information about the project, please visit our website at <http://www.atnet.org/CR4AT/home.html> or call Myisha Reed, Project Coordinator at: Phone (800) 390-2699, TDD (800) 900-0706 or e-mail: [myisha@cfilc.org](mailto:myisha@cfilc.org). You can also send mail to: 1029 J Street, Suite 120, Sacramento, CA 95814.

**NONE OF YOUR RESPONSES WILL IMPACT YOUR BENEFITS.**

- 1 DO YOU WANT TO PARTICIPATE IN THIS SURVEY? IF YES PLEASE CONTINUE.**
- 2 IF NO, STOP HERE. YOU CAN ALSO ASK FOR MORE INFORMATION- PLEASE SEE ABOVE FOR CONTACT INFORMATION.**

This survey uses the **shortened term “AT”** to refer to Assistive Technology.

**WHAT IS ASSISTIVE TECHNOLOGY? (A definition)**

Assistive Technology is “any item, piece of equipment, or product, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.” **You might call it a device, aid or tool.**

Some of these questions **MIGHT NOT** apply to you. You may skip questions or answer NA. Please **call us** if you need any help taking the survey.

1a. What language are you using for this survey?

- English
- Spanish
- Sign Language
- Other Language, specify: \_\_\_\_\_

1b. How are you filling out this survey? (Check **ALL** that apply)

- By telephone
- Through an interviewer
- On the Internet
- In writing, by myself

2. Do you use any technical aids or devices (AT)?

- Yes, Please continue to the next question.
- No, Please go to question #4.



3a. If you do not use any devices please go to question #4. This question is for people who do use devices. What do you use to help yourself? If you use more than one device, please identify the ONE device that is MOST IMPORTANT to you.

- |   |   |
|---|---|
| <input type="checkbox"/> Cane, walker or crutches   | <input type="checkbox"/> Hearing aid                          |
| <input type="checkbox"/> Manual wheelchair  | <input type="checkbox"/> Flashing / vibrating alerting device |
| <input type="checkbox"/> Scooter  | <input type="checkbox"/> White cane                           |
| <input type="checkbox"/> Electric wheelchair  | <input type="checkbox"/> Magnifiers                           |
| <input type="checkbox"/> Ventilator   | <input type="checkbox"/> TTY/text pager                       |
| <input type="checkbox"/> Oxygen   | <input type="checkbox"/> Relay services (video/TTY/Internet)  |
| <input type="checkbox"/> Computer - Off the shelf   | <input type="checkbox"/> Books on tape                        |
| <input type="checkbox"/> Specialized software   | <input type="checkbox"/> Reacher / Grabber                    |
| <input type="checkbox"/> Specialized hardware   | <input type="checkbox"/> Adapted vehicle                      |
| <input type="checkbox"/> Communication device (such as an electronic speech output board) | <input type="checkbox"/> Other, please specify                |
| <input type="checkbox"/> Adapted telephone  | _____   |
| <input type="checkbox"/> Adapted eating / cooking utensils                                | _____   |
| <input type="checkbox"/> Talking devices (i.e. Thermometers, scales)                      |   |

Questions 3b through 3j are about the device you just identified as the most important to you. Please skip to Question 4 if you did not name a device.

3b. How old is this device?

- One year old or less
- About 2 years old
- About 3 years old
- About 4 years old
- 5 to 10 years old
- More than 10 years old

3c. Where did you learn about the actual AT device? (Check **ALL** that apply)

- Health professional
- California Dept of Rehabilitation
- Family/Friend
- Yellow pages
- Independent Living Center
- AT Network
- Disability Business Technical Assistance Center
- Internet
- Catalogue
- Disability Expo / Conference
- Television or radio
- Other, please specify \_\_\_\_\_

3d. How satisfied are you with these issues regarding this device?

**1 is very dissatisfied and 5 is very satisfied.**

	Very dissatisfied					Very satisfied				
Overall experience	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Ability to choose item	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Help in finding, selecting, and using the device	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Cost of device	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How device works	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Repairs	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

3e. Which problems make using this device difficult?

**1 is a big problem or not easy at all and 5 is not a problem at all or very easy.**

	Big Problem					Not a Problem					
Time delay in getting equipment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Additional equipment needed	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Training not provided	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Equipment not fitting properly	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Frequent breakdowns	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Repairs taking too long	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> NA

3f. When this device breaks down, how long does it usually take to get it fixed and back to you for use? (Select **ONE**)

- Less than one week
- 1-2 weeks
- 3-4 weeks
- Over 4 weeks
- It has never broken down
- Don't know

3g. When (or if) this device breaks down, do you have a back-up device? (Select **ONE**)

- Yes
- No
- I don't know

3h. How much did this device cost?  
\$ \_\_\_\_\_  Don't know

3i. Who paid for this device? (Fill in a number "1" by the primary funding source, fill in a "2" by a secondary source, if applicable)

- \_\_\_ Private health insurance/HMO
- \_\_\_ Medicare
- \_\_\_ Medi-Cal
- \_\_\_ California Department of Rehabilitation
- \_\_\_ Employer
- \_\_\_ School system
- \_\_\_ Regional Center
- \_\_\_ California Children's Services
- \_\_\_ VA program
- \_\_\_ Independent Living Center
- \_\_\_ Community program
- \_\_\_ Free/Donated
- \_\_\_ Family
- \_\_\_ Self-pay
- \_\_\_ Other. Please specify \_\_\_\_\_

3j. Some people use more than one device to help themselves. If you use any other devices, please identify the ONE device that is SECOND MOST IMPORTANT to you. If you do not use any other devices, please skip to Question 4.

- |   |   |
|---|---|
| <input type="checkbox"/> Cane, walker or crutches   | <input type="checkbox"/> Hearing aid                          |
| <input type="checkbox"/> Manual wheelchair  | <input type="checkbox"/> Flashing / vibrating alerting device |
| <input type="checkbox"/> Scooter  | <input type="checkbox"/> White cane                           |
| <input type="checkbox"/> Electric wheelchair  | <input type="checkbox"/> Magnifiers                           |
| <input type="checkbox"/> Ventilator   | <input type="checkbox"/> TTY/text pager                       |
| <input type="checkbox"/> Oxygen   | <input type="checkbox"/> Relay services (video/TTY/Internet)  |
| <input type="checkbox"/> Computer - Off the shelf   | <input type="checkbox"/> Books on tape                        |
| <input type="checkbox"/> Specialized software   | <input type="checkbox"/> Reacher / Grabber                    |
| <input type="checkbox"/> Specialized hardware   | <input type="checkbox"/> Adapted vehicle                      |
| <input type="checkbox"/> Communication device (such as an electronic speech output board) | <input type="checkbox"/> Other, please specify                |
| <input type="checkbox"/> Adapted telephone  | _____   |
| <input type="checkbox"/> Adapted eating / cooking utensils                                | _____   |
| <input type="checkbox"/> Talking devices (i.e. Thermometers, scales)                      |   |

Questions 3k through 3r are about the device you just identified as the second most important to you. Please skip to Question 4 if you did not name a device.

3k. How old is this device?

- One year old or less
- About 2 years old
- About 3 years old
- About 4 years old
- 5 to 10 years old
- More than 10 years old

3l. Where did you hear about or find the actual AT device? (Check **ALL** that apply)

- Health professional
- California Dept of Rehabilitation
- Family/Friend
- Yellow pages
- Independent Living Center
- AT Network
- Disability Business Technical Assistance Center
- Internet
- Catalogue
- Disability Expo / Conference
- Television or radio
- Other, please specify \_\_\_\_\_

3m. How satisfied are you with these issues regarding this device?

**1 is very dissatisfied and 5 is very satisfied.**

	Very dissatisfied					Very satisfied				
Overall experience	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Ability to choose item	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Help in finding, selecting, and using the device	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Cost of device	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
How device works	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Repairs	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

3n. Which problems make using this device difficult?

**1 is a big problem or not easy at all and 5 is not a problem at all or very easy.**

	Big Problem					Not a Problem					
Time delay in getting equipment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Additional equipment needed	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Training not provided	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Equipment not fitting properly	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Frequent breakdowns	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
Repairs taking too long	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> NA

3o. When this device breaks down, how long does it usually take to get it fixed and back to you for use? (Select **ONE**)

- |   |                                       |
|---|---------------------------------------|
| <input type="checkbox"/> Less than one week       | <input type="checkbox"/> 1-2 weeks    |
| <input type="checkbox"/> 3-4 weeks                | <input type="checkbox"/> Over 4 weeks |
| <input type="checkbox"/> It has never broken down | <input type="checkbox"/> Don't know   |

3p. When (or if) your equipment breaks down, do you have a back-up device? (Select **ONE**)

- Yes             No             I don't know

3q. How much did this device cost?  
\$ \_\_\_\_\_  Don't know

3r. Who paid for this device? (Fill in a number "1" by the primary funding source, fill in a "2" by a secondary source, if applicable)

- \_\_\_ Private health insurance/HMO
- \_\_\_ Medicare
- \_\_\_ Medi-Cal
- \_\_\_ California Department of Rehabilitation
- \_\_\_ Employer
- \_\_\_ School system
- \_\_\_ Regional Center
- \_\_\_ California Children's Services
- \_\_\_ VA program
- \_\_\_ Independent Living Center
- \_\_\_ Community program
- \_\_\_ Free/Donated
- \_\_\_ Family
- \_\_\_ Self-pay
- \_\_\_ Other, please specify \_\_\_\_\_

3s. Do you use any other devices? (Please select **ALL** that apply)

- |   |   |
|---|---|
| <input type="checkbox"/> Cane, walker or crutches   | <input type="checkbox"/> Hearing aid                          |
| <input type="checkbox"/> Manual wheelchair  | <input type="checkbox"/> Flashing / vibrating alerting device |
| <input type="checkbox"/> Scooter  | <input type="checkbox"/> White cane                           |
| <input type="checkbox"/> Electric wheelchair  | <input type="checkbox"/> Magnifiers                           |
| <input type="checkbox"/> Ventilator   | <input type="checkbox"/> TTY/text pager                       |
| <input type="checkbox"/> Oxygen   | <input type="checkbox"/> Relay services (video/TTY/Internet)  |
| <input type="checkbox"/> Computer - Off the shelf   | <input type="checkbox"/> Books on tape                        |
| <input type="checkbox"/> Specialized software   | <input type="checkbox"/> Reacher / Grabber                    |
| <input type="checkbox"/> Specialized hardware   | <input type="checkbox"/> Adapted vehicle                      |
| <input type="checkbox"/> Communication device (such as an electronic speech output board) | <input type="checkbox"/> Other, please specify                |
| <input type="checkbox"/> Adapted telephone  | _____   |
| <input type="checkbox"/> Adapted eating / cooking utensils                                | _____   |
| <input type="checkbox"/> Talking devices (i.e. Thermometers, scales)                      |   |

3t. Did funding from other sources (not yourself) affect your AT choices?

- Yes       No       I don't know

3u. Did the price of the device affect your funding choices?

- Yes       No       I don't know

We want to know if your assistive technology (AT) needs have been met.

4a. Are there any AT devices and/or aids that you need but do not have?

- Yes       No      If no, skip to question 6.

4b. What aids or devices do you need? (Fill in the blank)

\_\_\_\_\_

\_\_\_\_\_

5. If you need technical aids or devices, but have not been able to get them, please mark all the reasons why: (You may select AS MANY AS NECESSARY)

- Not covered by insurance /Medi-Cal/Medicare
- Too expensive
- My condition is not serious enough
- I don't know where or how to obtain it
- Devices are not available in my area
- Some other reason. Specify: \_\_\_\_\_

6. Did you use AT devices in the past but then stop using them? If no, please skip to question 8

- Yes                       No                       Don't Know

7. Why did you stop using your AT?

\_\_\_\_\_

NA

8. Name an Assistive Technology (AT) device or equipment (you might not have it now) that could most help you to live independently in the community:

\_\_\_\_\_

Don't know

9. I feel isolated due to my disability: (Select **ONE**)

- Never. Please skip to Question 11.
- Rarely. Please skip to Question 11.
- Sometimes
- Most of the time
- Always
- Don't know



10. Does using AT help you cope with feeling isolated? (Select **ONE**)

- Never    Rarely    Sometimes    Most of the time    Always  
 Not applicable to me (IF you do not use AT you select this answer)

You might not use AT now, but if you think it would help in activities you do, please answer this question. **If not applicable please skip to #13**

11. For which activities in the home do you need AT? (Check **ALL** that apply to you):

- |   |   |
|---|---|
| <input type="checkbox"/> Cooking/eating         | <input type="checkbox"/> Cleaning   |
| <input type="checkbox"/> Parenting              | <input type="checkbox"/> Watching TV  |
| <input type="checkbox"/> Alerting/Signaling     | <input type="checkbox"/> Communicating  |
| <input type="checkbox"/> Getting around         | <input type="checkbox"/> Writing  |
| <input type="checkbox"/> Computer Use           | <input type="checkbox"/> Personal care - includes dressing,<br>toileting, bathing, brushing teeth, etc. |
| <input type="checkbox"/> Reading                |   |
| <input type="checkbox"/> Paying bills           |   |
| <input type="checkbox"/> Other- please describe |   |
- 

12. For which activities in the community do you need assistive technology (AT)? (Check **ALL** that apply to you)

- |   |  |
|---|--|
| <input type="checkbox"/> Errands                | <input type="checkbox"/> Shopping                                |
| <input type="checkbox"/> Family activities      | <input type="checkbox"/> Social/Community Activities             |
| <input type="checkbox"/> Health appointments    | <input type="checkbox"/> Taking classes                          |
| <input type="checkbox"/> Volunteering           | <input type="checkbox"/> Transportation                          |
| <input type="checkbox"/> Sports and Recreation  | <input type="checkbox"/> Communicating with others               |
| <input type="checkbox"/> Reading                | <input type="checkbox"/> Employment (any type-full or part-time) |
| <input type="checkbox"/> Other- please describe |  |
- 

CFILC would like to know **what changes would improve** the system that provides, funds and repairs devices and equipment (AT). Even if you do not use devices or AT right now, you still may have ideas.

13. If changes could be made to the AT system, what would you like to see happen? (Please check **ALL** that apply)

- |  |   |
|--|---|
| <input type="checkbox"/> Insurance system changed                  | <input type="checkbox"/> Case managers available  |
| <input type="checkbox"/> Try-out facilities for AT                 | <input type="checkbox"/> Persons with disabilities included as decision makers in funding process |
| <input type="checkbox"/> More affordable AT                        | <input type="checkbox"/> Devices easier to get  |
| <input type="checkbox"/> More universal design                     | <input type="checkbox"/> Persons with disabilities involved in the design process                 |
| <input type="checkbox"/> Expand definition of AT                   | <input type="checkbox"/> Training on use of equipment   |
| <input type="checkbox"/> Better system for repairs                 | <input type="checkbox"/> Don't know   |
| <input type="checkbox"/> National standardization for all agencies | <input type="checkbox"/> Other _____  |
| <input type="checkbox"/> Collaboration amongst agencies            |   |

14a. Do you use a TTY/TDD? (Select only **ONE**)

- Yes     No     Don't Know

**If you answered NO or DON'T KNOW please go to question #16. If you answered YES please answer #14b.**

14b. Do you use a relay service to communicate with people or businesses who don't have a TTY/TDD?

- Yes     No     Sometimes     I don't know

15. When using your TTY/TDD **are you able to reach people** (with or without a relay service) at the following places? (Select **ONE** answer for each area)

15a. Your health professional's office:

- Yes     Sometimes     No     NA

15b. Your school or your children's school:

- Yes     Sometimes     No     NA

15c. Businesses, restaurants or stores:

- Yes     Sometimes     No     NA

15d. Community services, such as seniors center:

- Yes     Sometimes     No     NA

15e. Government agencies, such as SSI:

- Yes     Sometimes     No     NA

**PLEASE REMEMBER: NO BENEFITS OR SERVICES ARE AFFECTED BY YOUR ANSWERS. WE WOULD LIKE TO KNOW HOW ASSISTIVE TECHNOLOGY IS USED FOR YOUR HEALTH.**

**Health**

16. Is your most important healthcare setting **accessible** to you? (Select **ONE**)

- Not at all    Mostly not    Somewhat    Mostly    Totally  
 Don't know

17. Does your health professional have a **weight scale** that weighs you properly? (Select only **ONE**)

- Yes    No    Don't Know

18a. Which of the following do **you use while at the health professional's office**? Please check **ALL** that apply:

- |   |  |
|---|--|
| <input type="checkbox"/> X-ray  | <input type="checkbox"/> Ramps   |
| <input type="checkbox"/> Scale  | <input type="checkbox"/> Braille/audio formats for information           |
| <input type="checkbox"/> Mammography  | <input type="checkbox"/> Non-English brochures/interpreters              |
| <input type="checkbox"/> Exam table   | <input type="checkbox"/> Lab tests – urine/blood testing, blood pressure |
| <input type="checkbox"/> Sign Language Interpreter                          | <input type="checkbox"/> None of the above                               |
| <input type="checkbox"/> Lifts to get on equipment or table from wheelchair | <input type="checkbox"/> Don't know                                      |
| <input type="checkbox"/> TTY's  | <input type="checkbox"/> Other _____                                     |
| <input type="checkbox"/> Electric doors                                     |  |
| <input type="checkbox"/> Hand/grab rails                                    |  |
| <input type="checkbox"/> Ultrasound machines                                |  |

18b. Which of the following **are you prevented from using because it isn't available or isn't accessible**? Please check **ALL** that apply:

- |   |  |
|---|--|
| <input type="checkbox"/> X-ray  | <input type="checkbox"/> Ramps   |
| <input type="checkbox"/> Scale  | <input type="checkbox"/> Braille/audio formats for information           |
| <input type="checkbox"/> Mammography  | <input type="checkbox"/> Non-English brochures/interpreters              |
| <input type="checkbox"/> Exam table   | <input type="checkbox"/> Lab tests – urine/blood testing, blood pressure |
| <input type="checkbox"/> Sign Language Interpreter                          | <input type="checkbox"/> None of the above                               |
| <input type="checkbox"/> Lifts to get on equipment or table from wheelchair | <input type="checkbox"/> Don't know                                      |
| <input type="checkbox"/> TTY's  | <input type="checkbox"/> Other _____                                     |
| <input type="checkbox"/> Electric doors                                     |  |
| <input type="checkbox"/> Hand/grab rails                                    |  |
| <input type="checkbox"/> Ultrasound machines                                |  |

19. In your opinion, **how knowledgeable is your primary health professional** about the range of Assistive Technologies? (Select **ONE**)

- Poor    Fair    Adequate    Excellent    Don't know

**IN THIS NEXT SECTION WE WANT TO KNOW ABOUT USING ASSISTIVE TECHNOLOGY FOR EMPLOYMENT. SOME OF THESE QUESTIONS MAY NOT APPLY TO YOU.**

**Employment**

20a. Please tell us about your employment situation. (Select all that apply)

- I work full time  
 I work part time  
 I am self-employed  
 I am working, but not as many hours as I would like  
 I am not currently working

20b Answer this question only if you are NOT currently working. (Select all that apply)

- I would prefer to work
- I feel I am able to work
- I am looking for work
- I am volunteering
- I am in school, training for a job
- None of the above

21. What assistive technology device or equipment would help you the most to get or keep a job, full or part time?

---

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- Don't know     Not applicable

22. How well has AT helped you in searching for a job? (Select **ONE**)

- Not at all    Very little    Average    A lot    Immensely  
 Not applicable

**If you are NOT working now, please go to question #29.**

23. Please check **ALL** devices or services you use to perform work duties:

- |   |  |
|---|--|
| <input type="checkbox"/> Magnifier  | <input type="checkbox"/> Telephone headset   |
| <input type="checkbox"/> Wheelchair   | <input type="checkbox"/> Mouth stick   |
| <input type="checkbox"/> Wrist splints  | <input type="checkbox"/> Support for personal functions:<br>eating, bathroom           |
| <input type="checkbox"/> Service animal   | <input type="checkbox"/> Personal assistant  |
| <input type="checkbox"/> Computer software to read the<br>screen in synthesized voice | <input type="checkbox"/> Adapted mouse   |
| <input type="checkbox"/> Computer hardware to output<br>in Braille                    | <input type="checkbox"/> Adapted computer screen, i.e.<br>larger screen or flat screen |
| <input type="checkbox"/> Voice activated software                                     | <input type="checkbox"/> Adapted keyboard  |
| <input type="checkbox"/> Hearing aid/amplification device                             | <input type="checkbox"/> Support for mental limitations -<br>job coaching              |
| <input type="checkbox"/> TTY/Pager/text communicator                                  | <input type="checkbox"/> Ergonomic table / chair                                       |
| <input type="checkbox"/> Automatic doors  | <input type="checkbox"/> Interpreters  |
| <input type="checkbox"/> Ramps  | <input type="checkbox"/> Readers   |
| <input type="checkbox"/> Tape recorder  | <input type="checkbox"/> Other _____   |
| <input type="checkbox"/> Amplified telephone  |  |

24. Have you ever requested an AT device as an accommodation from your employer?

- Yes     No     Don't Know     Not Applicable to me

**If yes, answer 25, If no, go to question 26**

25. What was the **outcome when you requested a device** from your employer? (Select as **MANY** as applicable)

- I got the device
- My requested was denied
- Referred to California Department of Rehabilitation
- Referred to someone for an evaluation
- Employer paid for all of it
- I was asked to pay part
- Employer said I had to buy it myself
- Other \_\_\_\_\_

26. How did you acquire the AT devices you use at work? (Select up to **THREE**)

- |  |   |
|--|---|
| <input type="checkbox"/> Employer                                | <input type="checkbox"/> Self-pay       |
| <input type="checkbox"/> Health Insurance                        | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> Donated                                 | <input type="checkbox"/> Other _____    |
| <input type="checkbox"/> California Department of Rehabilitation |   |

27. How well have AT devices helped you at work? (Select **ONE**)

- Not at all    Very little    Average    A lot    Immensely  
 Not applicable to me

Please answer this question if someone else paid for your device(s).

28. If you changed jobs tomorrow, could you take the devices paid for by your employer, Department of Rehabilitation, or someone else from your current job to another job? (Select **ONE**)

- Yes    No    Not sure    Not applicable

**This question is for anyone to answer.**

29. If you had to **choose what MOST limits you from working** to your fullest ability, it would be: (Please rank the top 3 reasons with 1 being the most limiting and 3 being the least limiting)

- My disability
- Lack of jobs
- Lack of education
- Problems with self-esteem
- Lack of assistive technology
- Attitudes of employers/the public
- Access in general to get in and around places
- Poverty, lack of financial stability
- Fear
- Potential loss of benefits / health coverage
- Communication Barriers
- Lack of transportation
- I do not feel limited
- Other \_\_\_\_\_

30. Did you know that employers can qualify for incentives to help pay for AT needed at work? (Select **ONE**)

- Yes       No

31. Please answer this question if you use AT when working or volunteering; if not, please go to the next question. In the last month, the **use of AT in my work/volunteering has resulted** in (Mark **ALL** that apply)

- |                          |                              |                                   |                             |
|--------------------------|------------------------------|-----------------------------------|-----------------------------|
| a. Improved productivity | <input type="checkbox"/> Yes | <input type="checkbox"/> Somewhat | <input type="checkbox"/> No |
| b. More paid work hours  | <input type="checkbox"/> Yes | <input type="checkbox"/> Somewhat | <input type="checkbox"/> No |
| c. Better attendance     | <input type="checkbox"/> Yes | <input type="checkbox"/> Somewhat | <input type="checkbox"/> No |
| d. Improved self-esteem  | <input type="checkbox"/> Yes | <input type="checkbox"/> Somewhat | <input type="checkbox"/> No |



If you **do not have devices now, but might in the future please continue** by answering the following questions. Current users of AT devices should also answer.

32. Would you be willing to pay a share of the cost if it would speed up the process of getting the AT you need?

- Yes, if I had the money     No     Don't know

33. How much would you be willing to spend if you had to pay for AT out of your own pocket? (Select only **ONE** range please.)

- |  |   |
|--|---|
| <input type="checkbox"/> \$1 - \$99      | <input type="checkbox"/> \$1600 - \$2000  |
| <input type="checkbox"/> \$100- \$499    | <input type="checkbox"/> More than \$2000 |
| <input type="checkbox"/> \$500 - \$999   | <input type="checkbox"/> Not applicable   |
| <input type="checkbox"/> \$1000 - \$1500 | <input type="checkbox"/> Don't know       |

**TO HELP US UNDERSTAND THE ANSWERS TO THIS SURVEY WE NEED TO KNOW INFORMATION ABOUT PEOPLE WHO FILLED OUT THE SURVEY. WE NEED SOME INFORMATION ABOUT YOUR PERSONAL SITUATION.**

34. Select **ALL** that apply:

- I am a parent of children under 18
- I am providing care for my own parents
- I am providing care for an adult with disabilities over 18
- A family member provides attendant care for me
- Paid caregivers (attendants and others) provide services to me
- I provide my own care

35. Select the **ONE** answer that **best describes** your living situation this month:

- I live independently by myself
- I live with at least one other person (roommate, spouse, child)
- I live with family (parents or adult relatives)
- I live with a live-in caretaker
- I am homeless
- I live in a group home or supervised living environment
- I live in an institution or nursing home
- None of the above

You may write in an answer that describes your situation best:

---

36. What is your Zip Code? \_\_\_\_\_

37. Select the **ONE** answer that best fits you:

- Male    Female    Transgender    Intersexed

38. Race & Ethnicity: (**Select as many as apply**)

- White
- Hawaiian/Pacific Islander
- Black/African American
- Asian
- American Indian/Alaska Native
- Hispanic/Latino/a
- Other, please specify \_\_\_\_\_
- Decline to State

39. Select **ONE** category for your education level:

- 1-8 years
- 9-12 years without diploma
- High school diploma or GED
- Some college but no bachelor's degree
- College graduate
- Graduate or professional degree

40. Please estimate annual income for your entire **household** in 2004, by selecting **ONE** category:

- |  |  |
|--|--|
| <input type="checkbox"/> Less than \$5,000 | <input type="checkbox"/> \$35,000-\$49,999 |
| <input type="checkbox"/> \$5,000-\$9,999   | <input type="checkbox"/> \$50,000-\$69,999 |
| <input type="checkbox"/> \$10,000-\$14,999 | <input type="checkbox"/> \$70,000-\$89,999 |
| <input type="checkbox"/> \$15,000-\$19,999 | <input type="checkbox"/> \$90,000 or more  |
| <input type="checkbox"/> \$20,000-\$24,999 | <input type="checkbox"/> Decline to state  |
| <input type="checkbox"/> \$25,000-\$34,999 | <input type="checkbox"/> Don't know        |

41. What is the **main source** of your income? (Select up to **TWO**)

- Employment
- Self-employment
- Pension/Retirement
- Federal government funding (SSI, SSDI TANF)
- Student Financial Aid
- Personal/family wealth
- Inheritance
- Child support
- Insurance settlement for injury
- Workers Compensation
- Don't know
- General Assistance
- Other \_\_\_\_\_

42. What best describes your major activities in 2004? (Check up to **TWO** areas)

- In school
- Working
- Volunteering
- Advocacy
- Parenting
- Keeping house
- Developing independence
- Caring for myself
- Caring for others
- Hobbies and leisure activities

43. This question is for people that **no longer work, but did in the past**. If you used to work, but don't any longer, is it because of: (Select **ONE**)

- I acquired a disability or it got worse
- Normal retirement
- Early retirement
- My disability benefits prevent me from working
- None of the above

44. How old are you today?

- 18-24    25-44    45-54    55-64    65-74    75-84    85+

45. At what age did you first start having any difficulty or activity limitation?

- Since birth    Under 18    18-44    45-54    55-64    65-74  
 75-84    85+

46. Which of the following statements apply to you (**Check all that apply**)

- I am blind
- I have low vision
- I am Deaf
- I am hard of hearing
- I don't speak
- People have trouble understanding me when I speak
- I can't get around without help or equipment
- I have trouble walking or am limited in mobility
- I have mental retardation
- I have a developmental disability
- I have a learning disability
- I have a mental health or psychiatric disability
- I have some other type of disability Specify: \_\_\_\_\_

The Community Research for Assistive Technology project would like to **thank you** for taking our survey. By filling out this survey, you are helping us get one step closer to understanding the gap in Assistive Technology for persons with disabilities.

A website ([www.atnet.org](http://www.atnet.org)) has also been developed to provide information about the AT Network. The AT Network website also provides articles on Assistive Technology and allows individuals to search online for Assistive Technology and services. Individuals can also receive information concerning Assistive Technology services and resources by calling the AT Network's Information and Referral Service at (800) 390-2699 or through its TDD line at (800) 900-0706. The AT Network can also be reached by fax at (916) 325-1699 and e-mail at [info@atnet.org](mailto:info@atnet.org).

Community Research for Assistive Technology – California AT & Consumers Survey

Please fill out this form to receive your \$20.00 gift. Two self-addressed postage paid envelopes have been provided. Mail the completed form in the first envelope. In the second envelope, mail your completed survey. This helps us to maintain your confidentiality. If no envelopes are attached, please send to:

CFILC/AT Survey  
1029 J Street, Suite 120  
Sacramento, CA 95814

If you would like to receive the \$20.00 gift, please provide your name and mailing address below:

Name: \_\_\_\_\_

Street Address or P.O. Box: \_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

**IMPORTANT REMINDER:** You may take this survey only ONE time, and only ONE check will be issued per person! You will receive your check from CFILC within 7 days of mailing. Checks will be mailed until monies run out.

# Tools for Living: Assistive Technology Experiences of Californians with Disabilities – Feedback Form

Thank you for reading the CR4AT publication, *Tools for Living: Assistive Technology Experiences of Californians with Disabilities*. 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       36-50       51 and up

C. I am from a/an       Rural       Urban       Suburban area

### D. Ethnicity

- |   |  |
|---|--|
| <input type="checkbox"/> African American | <input type="checkbox"/> Asian American/Pacific Islander |
| <input type="checkbox"/> Caucasian        | <input type="checkbox"/> Hispanic/Latino                 |
| <input type="checkbox"/> Mixed Race       | <input type="checkbox"/> American Indian                 |
| <input type="checkbox"/> Other            | <input type="checkbox"/> Decline to state                |

### E. I am a (check all that apply)

- |   |   |
|---|---|
| <input type="checkbox"/> Person with a disability | <input type="checkbox"/> Parent of a person with a disability |
| <input type="checkbox"/> Employer                 | <input type="checkbox"/> Educator                             |
| <input type="checkbox"/> Vendor/Service Provider  | <input type="checkbox"/> Researcher                           |

## F. Primary disability

- |                                   |                                      |
|-----------------------------------|--------------------------------------|
| <input type="checkbox"/> Mobility | <input type="checkbox"/> Sensory     |
| <input type="checkbox"/> Learning | <input type="checkbox"/> Psychiatric |
| <input type="checkbox"/> Other    | <input type="checkbox"/> 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?

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### 4) What issues are urgent now?

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### 5) Out of the urgent issues, which ones should be addressed now?

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**Please return survey to:**

Community Research for Assistive Technology Project  
Phyllis Dinse, Research Project Coordinator  
1029 J Street, Suite 120  
Sacramento, CA 95814

(916) 325-1690 (voice)

(916) 325-1695 (TDD)

(916) 325-1699 (fax)

[phyllis@cfilc.org](mailto:phyllis@cfilc.org)

**Thank you!**

