

CALIFORNIA ASSISTIVE TECHNOLOGY COALITION

Report #4

*Recommendations for Policymakers,
Regulators and Other Public and Private
Sector Decision-Makers on Steps That Can
Be Taken to Help California Meet the
Assistive Technology Needs of its Aging
and Disability Communities*

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Recommendations for Policymakers, Regulators and Other Public and Private Sector Decision-Makers on Steps That Can Be Taken to Help California Meet the Assistive Technology Needs of its Aging and Disability Communities

ABOUT THIS REPORT

This is the last in a series of four reports addressing the current and future assistive technology needs of California's aging and/or disabled populations.

The first report provided a trend analysis of California's aging and disabled populations, including the social, health, economic, policy, and regulatory challenges as they relate to assistive technology.

The second report took a deeper look at a number of issues that need to be addressed to enable aging adults and people with disabilities in California to maintain their independence and wellbeing. These issues include the need for awareness of and education about assistive technology, and the need to involve stakeholders in assistive technology research, design, evaluation and availability.

The third report reviewed how the assistive technology needs of California's aging and disability communities are currently being met, and focused on identifying gaps, barriers, challenges and unmet needs.

This last report, issued as the Coalition's final report, offers a composite of all recommendations issued by the Coalition for policymakers, regulators and other public and private sector decision-makers on steps that can be taken to help the state meet the assistive technology needs of its aging and disabled populations.

To access a copy of the Coalition's earlier reports, visit the Coalition's website at www.CATCoalition.org.

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I. Executive Summary

A number of advances in have been made in recent years in the development of Assistive Technology (AT). Research shows that AT is playing an increasingly important role in the lives of people who are aging and/or living with disabilities as a tool for helping them remain as independent as possible across their lifespan. But many challenges and barriers remain despite these advances.

The California Assistive Technology Coalition was formed in 2008 to advance the development, testing and use of assistive technology to help Californians who are aging and/or disabled live independently in their homes and to age in place to the extent possible. The Coalition was created through a partnership of the Independent Living Partnership, the California Department of Aging, and California State University, Fullerton. The goal of the Coalition's work over its three-year mandated lifespan was to assess the current state of AT availability and use in California, identify needs and gaps, and recommend steps that can be taken to address these needs and gaps. Drawing upon three previous reports, this fourth and final report provides the Coalition's recommendations for addressing the identified needs.

A major recommendation discussed in this report is the need for outreach and education initiatives to increase awareness of the benefits of AT, not only to enable those who are aging and/or disabled to live as independently as possible, but also as a tool for achieving health care delivery cost savings. Research finds that many people with disabilities, and especially aging adults and their caregivers, are unaware of the variety of AT devices that are available, especially the low- and no-tech devices and gadgets that can be used to make living at home safer and to maintain greater degrees of independence. Consumers are not only unaware of the existence of these devices, but also unaware of where to go to find and purchase them. The same is generally true for health care and social service providers. As a result, outreach and education initiatives also must focus on AT availability, informing consumers, caregivers, health care and social service providers and others on where to purchase AT devices. Education also must provide information on evaluation resources that can be accessed to ensure a proper fit between user and the device.

A second major recommendation addresses the need for better coordination and closer collaboration among appropriate stakeholders in the design, implementation, use, financing, and evaluation of AT. This includes not only consumers, but also caregivers, family members, teachers and other educators, employers, long-term care and other service providers, health care professionals, policymakers, public and private insurers, researchers, and industry leaders. Equally important is the

need to improve data collection systems that identify aging and disability trends and AT needs and usage.

The Coalition also recommends the following:

Removing Barriers to Independent Living at Home: A coordinated, well-planned effort needs to be undertaken by public health organizations, community planning organizations, the disability community, the construction industry, zoning officials, senior organizations, policymakers, researchers, consumers, and other appropriate community organizations to address the physical barriers in housing and home modification that make independent living difficult for many aging and/or disabled Californians.

Addressing Barriers to Access to Health Care: Public health practitioners, health-care providers, and community organizations need to take a more proactive role in removing environmental barriers and improving access to health care facilities for persons with disabilities and to develop a “disability competent” health care system that includes appropriate features to accommodate persons with disability. Efforts also need to be undertaken to make the use of telecommunication technology more widely available throughout California and to remove barriers to implementation and access.

Reducing Financial Barriers: Financial incentives for the use of AT must be provided both to users and their care givers as well as to health care professionals to encourage the more widespread use of AT. Broad-based efforts need to be undertaken to improve the coverage of AT by both private and public insurers. The scope of service of items covered through Medicare and MediCal should be expanded to include all disabilities that have a medical component, including vision, hearing, and physical and cognitive disabilities such as memory loss and TBI.

Promoting Research on the Use and Effectiveness of AT: More coordinated research is needed on Assistive Technology need, use and effectiveness. This research is important to determine the best equipment available to a particular person or for a specific disability and also to document the need for financial coverage of equipment.

Addressing Eligibility and Reimbursement Policies: Finally, the Centers for Medicare and Medicaid Services (CMS) should update its current outdated definitions of durable medical equipment and medical necessity to give consideration to increasing an individual’s functional status and to ensure that AT is eligible for coverage and reimbursement. More consistent and coherent federal

eligibility and reimbursement policies are needed. CMS should identify and implement mechanisms to pay for assistive devices for people who are blind or have vision impairments, hearing loss, cognitive impairments and other functional loss who are beneficiaries of the Medicaid and Medicare programs or other federally subsidized health care. Efforts need to be increased to require health insurers to cover various types of assistive technology.

II. Outreach and Education

Because the field is evolving rapidly, the need for education poses a significant challenge to ensuring more widespread access to and use of AT. Many people with disabilities, especially older adults, people with lower levels of education, minorities, cognitively impaired individuals, as well as their caregivers, lack an awareness of the potential benefits of the newer high-tech AT devices, how this technology can help them achieve greater independence and wellbeing, where to obtain AT devices, and how to pay for it if it is expensive. One particularly serious gap is the lack of awareness of the many low- to no-tech devices and gadgets that can be used to make living at home safer and to maintain greater degrees of independence.

Outreach and education initiatives should include not only users of AT but also their formal and informal caregivers, long-term care providers, health care providers, aging services providers (i.e., Area Agencies on Aging, senior centers, etc.), policymakers and AT industry leaders. To be effective, such initiatives should be offered by appropriate, credible professional organizations and consortiums.

The Coalition specifically recommends the following:

- Large-scale outreach and education initiatives are needed to make consumers aware of the broad range of AT devices that are available and how these devices can help them enhance their independence and well-being. To be effective, these initiatives must use a range of media and resources, including mainstream businesses, media and special events, and the social media such as Facebook and Twitter. Targets of education should include not only users of AT, but also their formal and informal caregivers, parents, school personnel, employers, long-term care providers, health care professionals, aging services providers, policymakers, and industry leaders. To gain wider acceptance and understanding of the benefits of AT, education programs must take a holistic approach that takes into consideration consumer lifestyles.
- Consumers also need to be educated on the effective use and maintenance of the various AT devices that are available, especially newer high-tech devices such as smartphones and other electronic devices that are increasingly incorporating AT apps and programs. It is well-known that when users experience difficulty in operating their devices or do not understand how to service or repair a device, the device may be abandoned and/or will not meet the need for which it was intended.

- Consumers, including health care and social service providers, should be made aware of “try-before-you-buy” opportunities for AT, including California’s AT Network Device Lending Library (DLL) Program (<https://exchange.atnet.org>)
- Education and awareness initiatives need to address the stigma often associated with the public use of AT, from wheelchairs and walkers to hearing aids, white canes and other devices and tools. These initiatives should emphasize the everyday benefits of AT devices, including increased mobility, more active participation in community life and greater independence.
- Health care providers and professionals should be a special target for outreach and education initiatives to increase awareness of the uses and value of AT in promoting independent living. Information needs to be included in undergraduate, graduate and continuing education courses. While health care providers generally do not need to be experts in these devices, they need to know what kinds of devices could help their patients or clients, including basic features that will ensure a good fit between the user and the device. Education initiatives also should focus on the best ways to present device usage to their patients and clients, i.e., patients are much more receptive to using a device when the provider stresses independence and wellbeing rather than focusing on disability and limitations.

The Coalition also recommends that champions in the California state legislature be identified and enlisted in education efforts targeting legislators, their staff and other policymakers on the benefits of AT. Administration leadership also needs to be informed of their potentially critical role in promoting AT that cuts across delivery silos. This includes California Dept. of Finance (DoF) leaders who are generally unaware of the potential cost-saving and other benefits associated with AT’s use. California policy and administration decision makers should also be educated on the actions that are incorporating telemonitoring and telehealth, medication dispensing devices, and other approaches into their state Medicaid waiver programs.

III. Independent Living

Overall, a coordinated, well-planned effort needs to be undertaken by public health organizations, community planning organizations, the aging and disability communities, the construction industry, zoning officials, senior organizations, policymakers, researchers, consumers and other relevant community organizations to address the physical barriers in housing and home modification that make

independent living difficult if not impossible for many aging and/or disabled Californians.

To increase independent living, the Coalition recommends the following:

- Build housing units with features that make them accessible to and appropriate for those who are aging and/or living with disabilities.
- Implement programs to educate people who are aging and/or living with disabilities about the benefits of home modifications.
- Remove barriers to the current housing problems facing older adults in California by providing (1) more affordable housing; (2) funding for home improvements and modifications; and (3) better linkages with community and health services.
- Remove barriers that prevent people from making needed home modifications by (1) educating individuals and organizations that can influence change on the benefits of home modification; (2) making home modifications more affordable; and (3) removing the regulatory obstacles to making home modifications.
- Make home modifications more affordable by improving the financial coverage of those modifications by both private and public insurers.

IV. Accessing Health Care Services

Survey data point to a serious lack of access in the older and disabled communities to health care and other needed resources by many older adults and/or those living with disabilities. Specific issues including lack of access to health care facilities, poor communication with providers, and difficulty in using examination tables, radiology equipment, exercise and rehabilitation equipment, weight scales, and toilet facilities.

Problems in accessing health care services are especially acute in rural areas, where residents tend to have higher poverty rates, a larger percentage of elderly, poorer health status indicators, fewer physicians doctors, hospitals and other health resources, and difficulty in accessing health care facilities because of distance and transportation issues.

The Coalition recommends that the following steps be taken to address these access issues:

- Telecommunication technology, specifically telemedicine, should be more widely available and used throughout California. The report *Advancing California's Leadership in Telehealth Policy: A Telehealth Model Statute & Other Policy Recommendations*, issued by the Center for Connected Health

Policy in February, 2011, contains specific steps that can be taken to remove barriers and increase the use of telehealth services.

- Public health practitioners, health-care providers and community organizations should take a more proactive role in removing environmental barriers and improving access to health care facilities for persons with disabilities and to develop a “disability competent” health care system that includes appropriate features to accommodate persons with disability.

V. Financing Challenges and Barriers

Consumers’ ability to purchase and maintain assistive technology is a major barrier to meeting the AT needs of California’s aging and disability communities. The Coalition recommends the following action steps to address these barriers:

- As indicated in the Coalition’s first report, the cost of many AT devices, especially the newer high-tech devices may be prohibitive for many people with disabilities and elderly persons who require them. In addition, the ability or lack of ability to pay for home modifications greatly influences the implementation of health and safety features that can help people with disabilities and elderly individuals lead independent and productive lives. Clearly, broad-based efforts need to be undertaken to improve the coverage of AT and home modifications by both private and public insurers. If the future needs of California’s aging and disability communities are to be successfully met, financial incentives need to be provided both to users and their care givers as well as to health care professionals.
- Many organizations accept donations of used assistive technology devices, including durable medical equipment, and after ensuring their usability, make them available to new users under reuse programs. Financial incentives for recycling and reusing such devices would help organizations expand these programs and would be a key step toward making such devices more widely available to consumers, especially low-income consumers. The AT Network’s Reuse Program is an example of programs that recycle AT (visit <http://atnet.org/resources/reuse-programs.php>).
- Broad-based efforts need to be undertaken to improve the coverage of AT by both private and public insurers. One possibility is through innovative reimbursement programs. Several states across the country have instituted innovative reimbursement programs for a number of assistive technologies. A study of 50 states conducted by the Center for Applied Special Technology (CAST) revealed some exemplary programs. States cited for their innovative efforts include Pennsylvania, New York, South Carolina,

and South Dakota. A listing of states and their reimbursement programs can be viewed at <http://www.aahsa.org/cast.aspx>

- Manufacturers of AT devices and special interest groups representing older adults and people with disabilities should work more closely with state and federal legislators and policymakers to implement changes in funding policies that would result in the more widespread availability and use of AT.
- The number of items covered under MediCal and Medicare should be expanded to include all disabilities that have a medical component, including vision, hearing, and physical and cognitive disabilities such as memory loss and TBI.
- More public funding is needed for disability research. See Research Challenges below.

VI. Research Challenges

Data on AT need, use and effectiveness in the United States is scarce, particularly in California. Furthermore, due to the rapid advances in technology, the limited information about AT devices that is available quickly becomes outdated. In general, more coordinated research is needed to determine the need for AT, how it is being used, and how it can be used more effectively. This research is important for two reasons. First, it can be used to determine which devices provide the best fit for certain needs. And second, it can be used to support advocacy activities advocating for improved financial coverage for AT use.

The Coalition recommends the following action steps to address the need for more and better research on AT.

- Given epidemiological trends in California, more research is needed to better understand the functional and chronic illness needs of both current and future users of AT. Clarifying distinctions among trends in chronic conditions, functional limitations and disability, and their interrelationships, will help policymakers and program officials anticipate the need for assistive technology devices.
- Recent small-scale research studies have helped to quantify the potential value of some assistive technologies for enhancing independence and reducing health care costs. These studies have raised questions about whether large-scale studies would produce similar results. This has led to a lack of consensus among many stakeholders, including policymakers, about the overall value of technology-enabling products and services, and this lack of consensus has negatively impacted funding for AT. Large scale studies are needed to provide convincing evidence that specific technologies have

the potential to increase independence, enhance health care quality, and lower health care costs.

- Due to its evolving nature, the field of AT is relatively unstructured. The inadequate infrastructure has special implications for more high-tech products and services related to telehealth. More research and development is needed in this area to allow different information systems to communicate with each other and to create an integrated, nationwide health information technology system.
- Current statistics on persons with disabilities are patched together from multiple, often inconsistent, surveys. A coordinated effort should be undertaken by researchers where a common framework is agreed upon for conducting surveys. This entails the use of consistent language and concepts and the inclusion of individuals of all ages and in all living situations. In addition, surveys should provide information that can be used to monitor the incidence, prevalence, severity, and duration of the various components of disability.
- Additional research is required to determine current AT usage patterns, consumer attitudes about AT, perceived obstacles to AT's use, potential consumer and health care cost benefits associated of the use of AT, and the future AT needs of the population.
- More research is needed to identify the barriers and problems individuals with disabilities encounter as they make transitions from early childhood, to school, to work, to older adulthood, and to retirement.
- Proactive involvement of end users in the design of AT and its practical application will maximize the likelihood of the technology's acceptance and effective use. Future research on assistive technologies needs to proactively involve age-appropriate participants in determining specific needs, device design and privacy preferences, as well as outcome evaluations. Testing labs, similar to the one established at California State University, Fullerton and those that have been implemented in other states, could be developed across California. These labs involve multi-disciplinary teams that include not only potential users, but also researchers, business partners and universities in the design, development, and deployment of AT innovations.

VII. Legislative and Regulatory Challenges and Barriers

Based on recommendations from The National Council on Disability (NCD) and the Institute of Medicine (IOM), the Coalition recommends the following legislative and regulatory changes to promote the more effective use of assistive technology:

- The Centers for Medicare and Medicaid Services (CMS) should update its definitions of durable medical equipment and medical necessity to ensure that the various technologies currently on the market, as well as those coming to market, are eligible for coverage and reimbursement.
- Current federal eligibility and reimbursement policies should be changed to make them more consistent and coherent.
- CMS should identify and implement mechanisms that can be used by Medicare, Medicaid and other federally subsidized health care programs to pay for assistive devices for people who are blind or have vision impairments, hearing loss, cognitive impairments and other functional loss.
- Health insurers should be encouraged to cover various types of assistive technology.
- Eliminate the long waiting periods for disability insurance.

VIII. Promoting the AT Industry as an Economic Engine and Source of Job Creation for California's Economy

When the Coalition was created in 2008, a stated Coalition goal was to promote the AT industry as a potential economic engine and source of job creation for California's economy. Framing the discussion was the belief that California was well positioned to take a leadership role in the AT arena, especially given the business and academic resources available in Silicon Valley and other parts of the state. Adding to this resource are the gerontological institutes and centers located at many California universities. It was noted that both the CA. Dept. of Aging and the Independent Living Partnership were well-positioned to promote an AT development initiative through California's Aging network and directly with aging adults. The Coalition saw substantial opportunities for building such an industry, and that the development of a vibrant AT industry could help fuel California's economy, including jobs. The Coalition recommended that financial investment firms, venture capitalists and even CalPERS should be encouraged to investment in this industry.

While the Coalition tabled further discussion about this area, one idea emerged that eventually was implemented. The Coalition had found that while university-based AT testing labs existed on the east coast, only one small-scale lab (Front Porch's Center for Technology Innovation and Wellbeing) existed in California. What the state lacked was a academically based facility that could bring AT developers together with end users to evaluate and validate real-life everyday uses of AT on a more widespread basis. The model for creating such a lab existed and could be replicated. In 2011, the Ruby Gerontology Center at California State University,

Fullerton, created such a lab. Although the mission and scope of the facility has recently shifted, it could serve as a model for other centers and labs.

The Coalition's first report, issued October 2010, addressed this and related area in depth and included several recommendations. The report can be accessed at www.catcoalition.org.

IX . Acknowledgements

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Finally, we wish to acknowledge the dedication and work of the Coalition's members who contributed their insights and ideas and helped make the Coalition's work and its reports possible.

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Following is a list of Coalition members who served on the Coalition over its three-year lifespan. Their professional affiliations and job titles are current as of the Coalition's last meeting.

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