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Assistive Technology Use in California – Gaps, Barriers, Challenges, and Unmet Needs

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CO-CONVENERS:

Independent Living Partnership (ILP)
California Department of Aging (CDA)
California State University, Fullerton (CSUF)

Assistive Technology Use in California – Gaps, Barriers, Challenges, and Unmet Needs

Prepared by Rita Strombeck, Ph.D.

ABOUT THIS REPORT

This is the third in a series of four reports regarding the current and future assistive technology needs of Californians. The first report provided a trend analysis of California's aging and disability communities, 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 older adults and people with disabilities in California to maintain their independence and wellbeing.

This report looks at the gaps, barriers, challenges, and unmet needs that require attention to enable older adults and people with disabilities in California to live independently and maintain wellbeing.

The last report will offer recommendations for policymakers, regulators and other public and private sector leaders on steps that can be taken to help the state meet the assistive technology needs of its aging and disability communities.

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

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I. Executive Summary

A number of advances have been made in recent years in the development of assistive technology (AT) and research shows that AT is playing an increasingly important role in the lives of people with disabilities to help them remain independent across the lifespan. Despite its potential and the progress that has been achieved, many challenges remain that require attention if we are to meet the growing needs of California's aging and disability communities.

This report looks at the following issues that require attention:

- Education Needs

- Independent Living Needs

- Lack of Access to Health Care, Social Services, and Other Resources

- Financing Challenges and Barriers

- Legal and Regulatory Challenges and Barriers

- Research Challenges

Recommendations are also included to help address the challenges identified. A salient feature that permeates all of the challenges is the need for greater coordination and 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 disability trends and AT needs and usage.

Education Needs. Because the field is evolving rapidly, the need for education poses a significant challenge to ensuring future use of AT. Many people with disabilities, especially older adults, people with lower levels of education, minorities, cognitively impaired individuals, and their caregivers, lack an awareness of the potential benefits of AT, especially newer high-tech AT. Targets of education should include not only users of AT, but also their formal and informal caregivers, teachers, employers, long-term care and other service providers, health care professionals, policymakers, public and private insurers,

industry leaders, and other appropriate stakeholders. Information should be communicated by appropriate credible organizations and explain how AT can help people with disabilities achieve greater independence and wellbeing, and how to pay for it.

Consumer need for information and education about AT resources and support systems is critical during transition points across the lifespan, i.e., when infants leave the regional center system and move into the Special Education K-12 system, when children then leave the Special Education support system, when illness or accidents occur, when people with disabilities move into a new residence, when they start a new job, or when they retire.

Education is also needed on how to effectively use and maintain the various AT devices that are available, especially the newer high-tech devices. In addition, education can also help address some of the stigma associated with AT and the negative attitudes held by some individuals regarding its use.

In addition to providing education to potential users of AT, training of health care professionals in the practical uses of technological devices will help increase their acceptability. Unfortunately, surveys show that a minority of AT users received information and support from their health care providers. According to the Institute of Medicine (IOM), the lack of awareness by health care professionals as a whole (especially those who are not rehabilitation specialists) of the range of assistive technologies and their potential uses is a significant barrier to the wider and more effective use of these technologies.

Because the field of assistive technology is evolving so rapidly, policymakers, insurers, and other appropriate stakeholders also need to be continually updated on the new developments in the field. Targeting these individuals with education about the benefits of AT, both in terms of cost savings and increased independence, will help them make better-informed, less-speculative decisions regarding the implementation of policies and regulations.

Recommendations. To address the lack of awareness regarding AT, several organizations, including National Task Force on Technology and Disability (NTFTD) and the IOM recommend that public campaigns be undertaken to educate and inform the public about the existence and benefits of AT. Potential mechanisms for distributing information and conducting the campaign include mainstream businesses, media and special events.

Education about AT among health care professionals is clearly needed. Information needs to be included in undergraduate, graduate, and continuing education courses. While health care professionals generally do not need to be experts in the technologies, they need to know what exists that might help their patients or clients and what basic features of a technology are important for a given patient.

Recognizing the need for increased education, a number of innovative programs have been undertaken across the country to educate consumers, the public, health care providers, policymakers, and other stakeholders. These programs can serve as a guide for California (pages 13 – 17).

Independent Living Needs. The Independent Living Movement grew out of the Disability Rights Movement, which began in the 1970s. The first Independent Living Center was established in 1972 in Berkeley, California. Since that time, a network of centers has been created across the state. Based on the dramatic shift in demographics across the country, Aging in Place is a phenomenon that has developed from the Independent Living Movement and is growing in importance. The term refers to the desire of older adults to live independently in their own housing and communities as long as possible.

There is increasing evidence to indicate that assistive technology plays a major role in helping to ensure that persons with disabilities can remain independent across the lifespan, especially when used for home modifications. Home modifications are adaptations made to existing home environments that can make it easier and safer for individuals with disabilities to perform daily activities. Studies have shown that home modification using AT can directly lead to a reduction in accidents, minimize the need for more costly personal care services, and delay institutionalization.

Unfortunately, most people with disabilities live in environments that are not conducive to achieving and maintaining independence and have made few or no basic modifications. The California Statewide Independent Living Needs Assessment (page 19), which looked at the needs of Californians with disabilities of all ages, provides a wide range of information regarding the basic independent living needs of people with disabilities, the barriers to independence and the gaps in services and supports in California. The three biggest barriers to home modification appear to be: 1) lack of information and education; 2) affordability; and 3) regulatory obstacles.

Recommendations. To address the existing problems related to independent living and increase the environmental supportiveness of new and existing housing, a 3-pronged *Aging in Place Initiative* has been proposed by the National Resource Center for Supportive Housing and Home Modification (see page 21). The Initiative includes recommendations stressing the need to increase education, improve funding, achieve regulatory reform, and increase research. The Initiative can serve as a guide for California to help enhance conditions for independent living.

Recognizing the benefits of aging in place, The California Commission on Aging has made several recommendations to address current housing problems facing older adults in the state. These recommendations are also supported by the California Statewide Independent Living Needs Assessment. In addition, a number of successful home modification programs have been implemented in various states across the country and can serve as models for California (pages 22 – 23).

Overall, 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 barriers to independent living in California.

Lack of Access to Health Care, Social Services, and Other Resources. Adequate access to health care can help people with disabilities lead healthier lives. However, people with disabilities and elderly persons encounter significant problems in accessing and using health care facilities. Surveys conducted in California reveal that individuals with disabilities encounter numerous difficulties entering facilities and examination rooms as well as using radiology equipment, physical examination tables, weight scales, exercise and rehabilitation equipment, and toilet facilities. Furthermore, persons with disabilities have been shown to be less likely than others to receive screenings for breast, cervical, and prostate cancer. Lack of accessibility to health services is particularly difficult for rural residents. The lawsuit filed in California against Kaiser Permanente in 2001 highlighted the lack of accessibility features for individuals with disabilities in health care facilities. Recognizing the need for improvement, Molina Healthcare in Long Beach created the Bridge2Access Statewide Advisory Committee to identify challenges it faces in providing health care to people with disabilities and older individuals.

In addition to environmental barriers which may impede access to health care facilities, many people with disabilities live in areas that are medically underserved. According to a report from the Office of Statewide Planning and Development (OSHPD), 49 of 58 counties in California have been identified as entirely or partially "medically underserved." One way to address the issue of accessibility is through the use of telecommunication technology such as telemedicine and telehealth. However, much remains to be done to make this technology more widely available throughout the state.

Recommendations. Findings from the surveys conducted in California and elsewhere underscore the need for public health practitioners, health-care providers, and community organizations to take a more proactive role in removing environmental barriers and improving access to health care facilities for persons with disabilities. Several researchers stress the need to develop a "disability competent" health care system that includes appropriate features to accommodate persons with disability. The guide *Removing Barriers to Health Care,* produced by The North Carolina Office on Disability and Health, can serve as a model for California (pages 25 – 26). In addition, efforts need to be undertaken to make the use of telecommunication technology more widely available throughout California. The report *Advancing California's Leadership in Telehealth Policy: A Telehealth Model Statute & Other Policy Recommendations* has been issued by the Center for Connected Health Policy. The report includes a number of recommendations that can be undertaken to achieve this goal (pages 27 – 28).

Financing Challenges and Barriers. The cost of many AT devices, especially the newer high-tech devices, may be prohibitive for many people with disabilities who require them. Over the past few years, iDevices (iPads, etc.) and other PDAs and their applications have seen an increase in usage by people with disabilities including older adults. But one major barrier to accessing and using these technologies is the lack of insurance coverage and other funding sources that could help consumers purchase and use these devices.

Financial barriers also impede the ability of persons with disabilities to pay for home modifications. Such modifications, with their health and safety features, could help people with disabilities and elderly individuals lead independent and productive lives. However, few Californians who could benefit from these modifications can afford them.

Recommendations. Broad-based efforts need to be undertaken to improve the coverage of AT by both private and public insurers. If the future needs of Californians of all ages with disabilities 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. Several states across the country have instituted innovative reimbursement programs for a number of assistive technologies. A study of 50 states conducted by the LeadingAge Center for Aging Services Technologies (CAST) revealed some exemplary programs that can provide guidance to California (see page 31).

Legal and Regulatory Challenges and Barriers. Over the years, the federal and local governments have taken a number of steps to address the needs of people with disabilities. There is growing understanding of the benefits of enabling people with disabilities and health problems to remain in their homes as long as possible.

Despite the increasing support for AT, much work remains to be done. There are several sources of funding for AT, including Medicare and Medicaid (Medi-Cal in California), the Department of Veterans' Affairs (of course, only for veterans), private insurance, some private and nonprofit organizations, and self-funding. Medicare and Medicaid, the biggest funders, cover assistive technology under their durable medical equipment (DME) benefit, but spending in this area accounts for only a small portion of overall program spending.

Medicare's narrow focus on restorative rather than compensatory care is a well-documented problem for people with chronic diseases and disabilities. In essence, the coverage process undervalues many important services, such as assistive technology, where demonstrated evidence of therapeutic effect is limited.

Recommendations. The National Council on Disability (NCD) recommends that the Centers for Medicare and Medicaid Services (CMS) should update its current definitions of durable medical equipment and medical necessity, which are outdated and give little consideration to increasing an individual's functional status. As a starting point, more consistent and coherent federal eligibility and reimbursement policies are needed. New definitions of medical necessity are needed to ensure that effective assistive technology is deemed eligible for coverage and reimbursement. NCD also recommends that CMS identify and implement mechanisms to pay for assistive devices for people who are blind or have vision impairments who are beneficiaries of the Medicaid and

Medicare programs or other federally subsidized health care. The Institute of Medicine (IOM) has also made a number of recommendations regarding AT and policy reform, including: more public funding for disability research; increased efforts to require health insurers to cover AT; elimination of long waiting periods for disability insurance; and improved education of consumers and professionals (page 34).

Based on findings from a survey conducted among U.S. manufacturers of AT, the Bureau of Industry and Security recommends that manufacturers of AT devices and interest groups representing people with disabilities work more closely with the state and federal governments to bring about changes in funding (page 35).

Research Challenges. Due to the evolving nature of AT, more research is required in several areas. Data on AT need, use, and effectiveness in the United States are scarce. Unfortunately, people with disabilities have too often been overlooked by health researchers. If the needs of Californians with disabilities are to be adequately addressed across the lifespan, broad-based research efforts in a variety of areas need to be undertaken to achieve this goal.

Significant variances have been reported in current disability data and projected future trends, both across the nation and in California. According to the Institute of Medicine (IOM), the major reasons for the variances are due to: 1) lack of consistent language used in surveys; and 2) inconsistency in the inclusion of all age groups and living situations.

Data on the use and need of assistive technology in the United States today is also difficult to estimate. Few studies of AT usage have been conducted. In general, they are limited to a specific disability population, age group, or kind of technology that either controls for the level of need or restricts the sample to a relatively homogenous disability population. In addition, it is believed that proactive involvement of persons who use AT devices in their design and implementation will maximize the likelihood of their acceptance and continued successful use of the technology.

Furthermore, 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. In several states, testing labs have been implemented that involve potential users and other stakeholders, including caregivers, health care providers, aging service providers,

manufacturers, and engineers, among others, in the design and evaluation of assistive technology. One example in California is the interdisciplinary CATLab (the California Assistive Technology Laboratory) that is being developed at California State University, Fullerton.

Research on outcomes can help ensure that AT is achieving its goals. Such research involves looking at a number of factors including: a) whether the technology is used or abandoned; b) whether AT leads to efficient completion of specific tasks/activities; c) if AT helps individuals achieve gainful employment; d) cost savings that are realized; e) how AT helps decrease caregiver support; f) how AT contributes to increased independence; and g) how AT enhances overall quality of life.

Recommendations. Additional research is required to determine current usage of AT, attitudes towards AT, perceived obstacles to use, future needs, and benefits of AT. This research needs to be well coordinated, more consistent in terms of concepts and language, and include individuals of all age and ethnic/cultural groups and in all living conditions, as well as other private and public stakeholders. A comprehensive framework would be very useful in achieving this goal. One example that could serve as a model for California is the Comprehensive Assistive Technology (CAT) model, developed in Scotland, which includes an ongoing dialogue among end-users, medical practitioners, clinical rehabilitation professionals, social support staff, and the engineering community (page 40).

II. Education Needs

Because the field is evolving so rapidly, the need for information and education poses a significant challenge to ensuring the future use of AT. Targets of education need to include not only users of AT, but their formal and informal caregivers, teachers, employers, long-term care and other service providers, health care professionals, policymakers, public and private insurers, industry leaders, and other appropriate stakeholders. Information should be communicated by appropriate credible organizations such as AARP, LeadingAge (formerly the American Association of Homes and Services for the Aging) and the LeadingAge Center for Aging Services Technologies (CAST), the National Association for Home Care (NAHC), the Visiting Nurses Associations of America (VNAA), and other professional organizations and consortiums. (1)

Consumer and Public Awareness of and Education About AT. The use of assistive technology has the potential to increase independence for people with disabilities across the lifespan. However, many people with disabilities, especially older adults, people with lower levels of education, minorities, cognitively impaired individuals, and their caregivers, lack the awareness of the potential benefits of AT, especially the newer high-tech AT devices, how this technology can help them achieve greater independence and wellbeing, and how to pay for it. (2-3)

Consumer need for information and education about AT resources and support systems can become critical during transition points, i.e., when infants leave the regional center system and move into the Special Education K-12 system, when children then leave the Special Education support system, when illness or accidents occur, when people with disabilities move into a new residence, when they start a new job, or when they retire. Even though a wide range of social service and advocacy programs and organizations are available (both public and private) to help people with disabilities achieve independence, many of these services and programs are often underutilized. The Institute of Medicine (IOM) has found a number of barriers facing young people with disabilities in transition, including, among other factors, lack of education by both family members and primary care providers (see Education of Health Care Providers page 16). (4)

A recent small pilot study showed that Web-based family-centered education and support have become integral to assistive technology (AT) decision making, especially regarding the needs of and resources for young children. While the use of computer sources to find and share information related to AT appears helpful, more research is needed to understand how families might be assisted and how more effective family-centered Web-based and related technology supports might be developed. (5)

The Americans with Disabilities Act (ADA) requires employers to eliminate discriminatory practices and promote equal opportunity by making reasonable accommodations for persons with disabilities. Again, lack of knowledge about AT benefits and resources, by both job seekers and employers, represents a major barrier to independence on the job. In some states, efforts are being made to improve education. For example, The Pennsylvania Assistive Technology and Employment Collaborative is a network of Pennsylvania organizations that provides information to employers and others on assistive technology and how it can help individuals with disabilities in employment. Its

goal is to increase understanding of the employer's responsibility for providing assistive technology and how to locate, try, and buy assistive technology devices and services, including employer resources and incentives. For information on Collaborative members, resources and contact information, go here: http://disabilities.temple.edu/programs/assistive/atwork/.

Education is also needed on how to effectively use and maintain the various AT devices that are available, especially the newer high-tech devices. If users experience difficulty with utilization or do not understand how to service or repair a device, it may be abandoned. (6) The way the use of new technology is taught is critical to an individual's comprehension and use of the device, especially older adults, and they may require unique training approaches based on interactive adult learning principles. (7)

AT usage can be viewed positively, as a way to regain and maintain independence, or negatively, as a symbol of declining function and abilities. The social stigma that many persons attach to AT devices, especially mobility devices, plays a significant role in whether or not devices are accepted into an individual's daily life. Education can help address the attitudinal barrier to AT usage. (8)

In addition to attitudinal barriers, many people with disabilities are unsure of the appropriateness of AT devices in addressing their limitations. Because many devices are expensive, programs that offer consumers the opportunity to try an assistive or adaptive device before they purchase it help consumers find the best fit and save money. While a "try-before-you-buy" program exists in California, many older adults and people with disabilities are unaware of its existence. The Device Lending Library (DLL) program is a service of the AT Network. It operates under a contract with the California Department of Rehabilitation with funding from the Assistive Technology Act of 2004. The DLL program loans devices to consumers so they can test and evaluate their appropriateness before they buy them. The program also enables consumers to borrow devices on a short-term loan basis to meet temporary needs. Devices are available through the AT Exchange website and/or through contact with the 13 DLLs throughout the state (https://exchange.atnet.org/welcome.aspx). Efforts should be made to more widely publicize the availability of the program among California residents. Similar programs exist in other states. Some of these programs and general information about device loan programs are on this link from RESNA: http://www.resnaprojects.org/documents/queries/getDocsByKeyword.php?key word=Device+Loan.

Another program is the Network of Care. (http://networkofcare.org/home.cfm)
This model program operates in several states, including California, and
highlights resources, including assistive technology for Seniors and People with
Disabilities. The following link shows the assistive technology component of
the Riverside County, California program:
http://riverside.networkofcare.org/aging/assistive/index.cfm

The National Task Force on Technology and Disability (NTFTD) recommends
that a large-scale campaign be undertaken to educate and inform the public
about the existence and benefits of AT. Following are suggestions by NTFTD
to assist in strengthening awareness:

- This effort should be done in consultation with AT companies, their trade
  associations, media organizations, disability consumer groups and state
  AT programs dedicated to public interest;
- The campaign should inform consumers about availability and features;
- The campaign should work to increase the value of diversity, counter any
  stigma associated with AT and aim at the broadest possible audience;
  and
- The campaign should encourage the development of technology that can
  enable people with disabilities to be more independent.

Potential mechanisms for distributing information and conducting the campaign
include mainstream businesses, media and special events:

- A high-tech, hands-on demonstration-based mobile road show would
  familiarize the public with "cutting-edge" AT equipment;
- High-impact presence at industry trade shows;
- Articles in popular magazines, like *Readers Digest*, discussing "simple"
  or "easier" ways to do things;
- Media approaches that reach the schools, e.g., *Weekly Readers*, Channel
  One, etc.;
- Media spots that feature aging movie stars using AT devices;
- TV spots, including support for disability-oriented cable shows and
  Internet video;
- Displays and accessible kiosks in high traffic locations such as malls,
  banks, grocery stores and information technology retail outlets;
- A poster campaign;
- Involvement of public and other libraries;
- Sponsor benefit programs; and

- Engagement of targeted senior citizen benefit providers such as AARP.

In addition, NTFTD recommends that mechanisms be developed to empower consumers with information. Tools or resources for consumers to find products that have the accessibility features they need should use clear, agreed-upon terminology, contain information about compatibility with AT and be available to people with different levels of technological capability. These mechanisms should provide:

- A framework for shared terminology from an industry and consumer standpoint;
- A format or platform to help people get accurate information; and
- Product support and advocacy.

More detailed information is available at http://www.ntftd.com/report.htm

The Institute of Medicine (IOM) also recommends that a widespread campaign be undertaken to assist people with disabilities, family members and friends, and health professionals in learning about the existence and range of potentially beneficial mainstream and assistive technologies and the ways in which consumers and professionals can obtain additional, up-to-date information about available technologies and products. (9)

According to the IOM, a large-scale, long-term, repetitive public media campaign has the potential to increase the acceptance of assistive technologies by highlighting what products are available to "make life easier" and conveying the message that it is normal to use smart technologies. Promotions could show celebrities using technologies and natural-looking aids. Another strategy might be to persuade the producers of popular television programs to show the unobtrusive, routine use of assistive technologies. The idea is to help people feel more comfortable using technologies that may allow them to live independently longer or to stay with their families longer by reducing the amount of informal caregiving needed. If a public awareness campaign identifies unattractive product design as a problem, then that knowledge can also guide contacts with manufacturers and designers about how to modify the products to reduce this barrier to the use of helpful technologies.

The consumer component of a public awareness campaign would target not only the lack of knowledge about the available technologies, but would also help people assess whether they have developed functional deficits for which helpful products exist. The campaign would include guidance for people on:

- recognizing their potential needs for assistive technology;
- finding useful information about available technologies and their pluses and minuses;
- identifying and evaluating specific products;
- locating sources of financial assistance; and
- working with health care professionals, suppliers, manufacturers, and others to obtain, maintain, adjust, repair, or replace equipment.

Education of Health Care Providers. Research indicates that the primary source of information regarding assistive technologies is physicians and other medical personnel. (10) In addition to providing education to potential users of AT, training of health care professionals in the practical uses of technological devices will help increase their acceptability. (11) It has also been shown that, when health care providers discuss the use of AT, patients are much more receptive to using a device when the provider stresses independence and wellbeing rather than focusing on disability and limitations. (12) Unfortunately, a national survey of more than 1400 individuals with disabilities conducted by the University of Michigan found that a sizeable number of respondents reported that they had received little or no information about assistive technologies from their health care providers. (13)

According to the IOM, the lack of awareness by health care professionals as a whole (especially those who are not rehabilitation specialists), of the range of assistive technologies and their potential uses is a significant barrier to the wider and more effective use of these technologies. The IOM also found that primary care providers are poorly prepared to address the needs of people with disabilities who are in transition. (14)

Addressing this lack of awareness will involve efforts on several fronts, including the undergraduate, graduate, and continuing education of health professionals. Strategies need to be identified to provide quick, interesting, and effective means of injecting information about helpful technologies and methods of assessing consumer needs into education programs. While health care professionals generally do not need to be experts in the technologies, they need to know what exists that might help their patients or clients and what basic features of a technology are important for a given patient.

In sum, increasing consumer and professional awareness of assistive technologies should have a positive effect on the use of these technologies and, in turn, on people's functioning and independence.

Education of Policymakers and Other Stakeholders. Although there is mounting evidence that AT can result not only in increased independence, but also cost savings, research is still relatively sparse (see below Research Challenges). More broad-based research on the positive outcomes of AT usage, especially regarding reduced health care costs, is needed to help educate and influence policymakers to make better-informed, less-speculative decisions regarding various technologies.

Furthermore, because of the rapidly evolving field of assistive technology, policymakers, insurers, and other appropriate stakeholders also need to be continually updated on the new developments in the field. One program that has been implemented to help educate policymakers and other stakeholders is "Partners in Policymaking," created by the Minnesota Governor's Council on Developmental Disabilities (MGCDD) and replicated in California. See http://www.partnersinpolicymaking.com/. Partners is an innovative, competency-based leadership training program for adults with disabilities and parents of young children with developmental disabilities focused on "teaching best practices in disability, and the competencies of influencing public officials." Graduates of the training program are encouraged to become active partners with those who make policy by informing them about current resources and the benefits of AT.

Based on The Technology Related Assistance for Individuals with Disabilities Act (Tech Act), a number of other innovative programs have been undertaken across the country to educate consumers, the public, health care providers, policymakers, and other stakeholders. These can be viewed at http://assistivetech.net/webresources/stateTechActProjects.php.

III. Independent Living Needs

The concept of independent living applies to people of all ages and encompasses two main points. According to the American Heritage Dictionary (2009), it is seen as:

- A living arrangement that maximizes independence and self-determination, especially of disabled persons living in a community instead of in a medical facility; and
- A social movement asserting that people with disabilities should have the same civil rights and life choices as people without disabilities.

The Independent Living Movement grew out of the Disability Rights Movement, which began in the 1970s. The first Independent Living Center was established in 1972 in Berkeley, California. Since that time, a network of centers has been created across the state. (For a listing by county, go to http://www.rehab.cahwnet.gov/ils/ilclist.htm)

Based on the dramatic shift in demographics across the country, aging in place is a phenomenon that has developed from the Independent Living Movement and is growing in importance. The term refers to the desire of older adults to live independently in their own housing and communities as long as possible. (15) A National Aging in Place Council (NAPC) has been created, with chapters across the country, including California. NAPC is a collaborative senior support network that was founded on the belief that most older Americans want to remain in their homes for as long as possible, but lack awareness of home and community-based services that make independent living possible. (See http://www.ageinplace.org and click on Products on the left menu bar for AT Product providers.) NAPC also sponsors an annual Aging in Place Week. The goal of Aging in Place Week, held in October, is to incorporate business to business, business to consumer, and media events…to… create local awareness among seniors and community involvement. For more information, see:
http://www.ageinplace.org/naipc_week/naip_week_2010.aspx.

There is increasing evidence to indicate that assistive technology plays a major role in helping to ensure that persons with disabilities can remain independent across the lifespan. Nevertheless, in addition to the need for more education, other barriers exist that impede the achievement of this goal.

A survey conducted in 2005 among close to 2,000 consumers of Independent Living Centers (ILC) throughout California, aged 18 and older, revealed large differences in technology usage by age, race, ethnicity, education, income, and type and severity of disability. (16)

According to the survey, factors that appear to put people with disabilities at a disadvantage in accessing and using assistive devices include lower educational attainment, racial or ethnic minority status, lower household income, later disability onset, and disability related to mental as opposed to physical or sensory functioning. Findings also revealed that usage of AT increases with age. The survey found that 68% of respondents of all ages used at least one AT device, especially low-tech devices. The main AT devices used by participants addressed mobility, vision, hearing, mental health, cognitive, and speech impairments. Usage of high-tech devices declined with age, however.

In 2003-2004, a *Statewide Independent Living Needs Assessment* was conducted among persons with disability in California. (17) A number of overall improvements were recommended to meet the needs of people with disabilities in the state. With regard to AT, the following recommendations were made:

- Increased discounts for the purchase of a vehicle with appropriate assistive technology adaptations;
- Increased accessibility to electric scooters;
- Expanded sources for durable medical equipment that accept Medi-Cal;
- Expanded insurance caps for power wheelchairs and other durable medical equipment that exceed current caps;
- Expanded funding for AT, including AT evaluations, training, and maintenance;
- Expanded opportunities to access the Internet, including training and development of more public access locations;
- Improved information on communication technology available from the phone company;
- Increased access to pagers such as Sidekick or Blackberry that are free or inexpensive;
- Increased accessibility to Acrobat reader PDF files that have the ability to enlarge on screen AND to print in large print; and
- Improved access to at-home entertainment, including reading, radio, television: "The blind need additional support with talking books and Braille books; people who are deaf need TV captioning."

Despite the progress that has been made in the past few decades to enable persons of all ages with disabilities across the country and in California to live independently, barriers are still encountered. For example, in January, 2011,

Medicare started a new "competitive bidding" program for durable medical equipment and supplies in nine metropolitan regions. This program will affect thousands of Medicare beneficiaries who use the following equipment and related services and supplies: power wheelchairs, walkers, oxygen, CPAP and respiratory assistive devices, hospital beds, enteral nutrients (tube feeding), support surfaces, and mail-order diabetic supplies. While the program is supposed to help reduce spending in Medicare, it may result in increased spending at the emergency rooms and delayed transition from hospital care to home care. (For more information, see "CMS AT Competitive Bidding" in the Appendix, page 50.)

Home Modifications. Environmental barriers can significantly reduce the independence of people with disabilities living in a residential setting. Removing these barriers through home modification is one way to increase independence. Home modifications are adaptations made to existing home environments that can make it easier and safer for individuals with disabilities to perform daily activities such as bathing, cooking, and climbing stairs and generally remain independent. These modifications can range from inexpensive railings, rearranged furniture, or extra lighting, to more costly ramps, elevators, roll-in showers, and fully remodeled bathrooms and kitchens. A number of studies have shown that home modification using AT can directly lead to a reduction in accidents, minimize the need for more costly personal care services, and delay institutionalization. (18)

Unfortunately, most people with disabilities live in environments that are not conducive to achieving and maintaining independence and have made few or no basic modifications. Many, if not most, homes are not equipped to support the needs of persons with disabilities. In fact, the overwhelming majority of housing in which Americans reside has been developed for independent residents. (19) Although the Fair Housing Amendments Act of 1988 (U.S. Code, Title 42, Section 3604) prohibits discrimination against people with disabilities in a variety of housing settings, a major barrier to implementing home modifications for both homeowners and renters is the cost of complex changes to the home.

The Los Angeles County Health Survey, conducted in 2002-2003 among more than 8,000 individuals over age 18 found that, among respondents to the survey who reported having a disability (1,333), almost 25% (311) reported they needed home modifications, but did not have them. (20) The need for home

modifications was higher among low-income individuals and Hispanics and African-Americans.

The three biggest barriers to home modification appear to be: 1) lack of information and education; 2) affordability; and 3) regulatory obstacles. To address the existing problems related to independent living and increase the environmental supportiveness of new and existing housing, a three-pronged *Aging in Place Initiative* has been proposed by the National Resource Center for Supportive Housing and Home Modification. (21) Although the proposal was designed to address the needs of older adults, it is applicable to persons with disabilities of all ages. The proposal includes the following recommendations:

1. Increase the availability of home modifications by:
   a. Raising public awareness about the benefits of home modifications;
   b. Enhancing planning and coordination efforts;
   c. Increasing funding for home modifications by reforming Medicare and Medicaid, the use of waiver programs, a change in income tax rules, and the use of reverse mortgages;
   d. Creating demonstration projects that test innovative service delivery models and establish "best practices"; and
   e. Using large datasets such as the American Housing Survey to analyze the need for and the effectiveness of home modification.

2. Retrofit existing multi-family units by:
   a. Increasing funds for modernization of older, federally assisted housing stock with an emphasis on creating a supportive environment for frail older persons;
   b. Converting some government subsidized housing for the elderly into assisted living; and
   c. Providing incentives to owners and sponsors of apartment buildings to modify their buildings to meet the needs of persons with disabilities.

3. Facilitate suitable housing by:
   a. Offering federal tax incentives for the provision of visitability and universal design features in new single-family homes and small apartments; and

b. Waiving permit fees for the construction and rehabilitation of homes that will incorporate visitability and universal design.

To achieve these goals, 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.

Recognizing the benefits of aging in place, the California Commission on Aging has made several recommendations to address current housing problems facing older adults in the state. (22) Once again, although these recommendations were intended to address the needs of older adults, they are applicable to persons of all ages. These recommendations include the need to provide:

- more affordable housing;
- funding for home improvements and modifications; and
- better linkage with community and health services.

These recommendations are also supported by the California Statewide Independent Living Needs Assessment (cited above, p.19) which looked at the needs of Californians with disabilities of all ages. The report provides a wide range of information regarding the basic independent living needs of people with disabilities, the barriers to independence and the gaps in services and supports in California. (23) In addition, the California Department of Housing and Community Development has compiled a comprehensive listing of resources, guidelines, examples of successful programs that have been implemented across the country, and toolkits that address the current and future problems related to environmental modifications to promote community-based living for people with disabilities of all ages. (24) This comprehensive report can be viewed at: http://www.hcd.ca.gov/hpd/aginginplace.pdf.

A number of successful home modification programs have been implemented in various states across the country. For example, Access Remodeling (AR) is a private for-profit business that has provided residential accessibility services to clients in the Washington, D.C. and Potomac, Maryland areas since 1987. AR provides remodeling services not only for older adults but also for younger individuals. Services include home visits, environmental assessments, and the installation of home modifications. (25)

To better understand how home modification programs operate, a telephone survey was conducted of over 200 programs. This survey was performed by the USC Andrus Gerontology Center's National Resource Center on Supportive Housing and Home Modification. Questions asked related to targeting, assessment, funding, and types of modifications performed. The information was analyzed using descriptive statistics to create a national profile of home modification programs. Then, five cases were selected as exemplary/successful models of service delivery and case studies were conducted. Three of the programs (South East Senior Housing Initiative in Baltimore, the Philadelphia Corporation on Aging, and the Santa Clarita Valley Commission on Aging in Southern California) are non-profits and two are for-profit (Extended Home Living Services and Access Remodeling). View this report at http://www.usc.edu/dept/gero/nrcshhm/research/pages/hm_programs.htm.

One such exemplary model is the Livable Design National Demonstration Home, located on the EskatonVillage Roseville campus, north of Sacramento. "This home represents the future of independent living…combining innovative universal design, breakthrough technologies and green living features with beauty, simplicity and comfort." Check out the website at http://www.eskaton.org/national-demo-home.html and this link at http://www.livabledesign.net/demohome.html. This national model for universal design standards earned the 2009 AARP/NAHB Livable Communities Award and the 2009 NAHB 50+ Housing Award. For more information, also see: http://www.livabledesign.com/profiles.html.

IV. Lack of Access to Health Care, Social Services and Other Resources

It is important for people with disabilities to have access to adequate health care, social services, and other related resources to help them lead healthy lives. However, due to problems encountered in accessing health care facilities and poor communication with providers, substantial disparities in health behaviors and overall health status exist between persons with and without disabilities. (26) Increasing access to health and wellness treatment programs for persons with disabilities and reducing the proportion of persons with disabilities who report environmental barriers to participation in daily activities are goals of *Healthy People 2010* (objectives 6-12). (27)

Although research on environmental barriers to health care facilities for people with disabilities has been limited, some small national studies have reported widespread problems with access to health care facilities, communication with providers, as well as difficulty with physical examination tables, radiology equipment, exercise and rehabilitation equipment, weight scales, and toilet facilities. (28) Furthermore, compared with urban Americans, studies show that rural residents have higher poverty rates, a larger percentage of elderly, tend to be in poorer health, have fewer doctors, hospitals, and other health resources, and face more difficulty gaining access to health facilities. (29) These conditions exist in California as well, as evidenced by the Needs Assessment for People Living With Disabilities conducted by the State Independent Living Council (cited above, p.19) in 2003-2004 and again in 2010.

In the 2002-2003 Los Angeles County Health Survey, 22% of persons with disabilities reported having difficulty accessing a health-care provider's office because of the physical layout or location of the property and almost 13% reported unfair treatment at a provider's office because of a disability. These difficulties led to an increase in the severity of disability. In addition, the survey reported that people with a disability were significantly less likely than others to have received screenings for breast, cervical, or prostate cancer. (30)

The Los Angeles County Health Survey is consistent with another more recent survey of 400 Californians with mobility limitations which found that one in five respondents had problems with the main entrance to their physician's office and one-third had problems entering examination rooms. (31) Other problems cited in the survey included difficulty in the use of mammography and other imaging equipment by people in wheelchairs (45%); difficulty using physical examination tables (69%); inaccessible weight scales (60%); and difficulty reading medical information by people with vision problems (90%).

Enactment of the Americans with Disability Act in 1991 has helped increase awareness of the barriers facing persons with disabilities in accessing health care and other community facilities. Nevertheless, much remains to be done. The continued lack of accessibility features in places where people might expect them – notably, hospitals – was highlighted in a lawsuit filed against Kaiser Permanente in 2001. In the settlement, the organization agreed to provide accessible medical equipment in its facilities, survey its facilities and policies for barriers and remove such barriers, and provide appropriate staff training. The plaintiff organization is currently monitoring progress by Kaiser Permanente in meeting the terms of the settlement. For more information on the case, go to:

http://www.dralegal.org/cases/health_insurance/metzler_v_kaiser.php.

Researchers have stressed the need to develop a "disability competent" health care system that includes appropriate features for people with disabilities. (32) Findings from the Los Angeles County Health Survey underscore the need for public health practitioners, health-care providers, and community organizations to take a proactive role in removing environmental barriers. In addition, to increase access to information, it is recommended that public health practitioners compile lists of community-related disability resource information and distribute them to local health-care centers and physicians' offices.
One example of a model response to this issue is the Bridge2Access Statewide Advisory Committee, created by Molina Healthcare, headquartered in Long Beach, CA, to bring stakeholders to the table to help Molina identify the challenges it faces in providing appropriate health care to aging and disability communities. For more information on Molina, visit their website, http://www.molinahealthcare.com/Pages/index.aspx.

The North Carolina Office on Disability and Health has produced a guide called *Removing Barriers to Health Care* to enhance accessibility to health care facilities by people with disabilities. The guide provides a range of recommendations regarding both environmental features and training of providers, including the following:

- Weather protection at entrance doors,
- Power door operators at interior and exterior entrances,
- Spaces left open but dispersed in waiting areas where wheelchair users can sit out of traffic lanes but with other people,
- Chairs for use by people who cannot stand while transacting business,
- Chairs that can be set at different heights for use by children, adults and older people, some equipped with arm rests for those who need assistance rising to their feet,
- Scales that allow people with difficulty standing to hold on, and one that allows people to be weighed while sitting in a wheelchair,
- Motorized, adjustable-height treatment and examining tables and chairs,
- Mammography machines that can be used on a woman in a seated position,
- A portable, amplified communication system or device with volume control at service desks and treatment spaces for people who are hard of hearing,

- More than one accessible toilet and dressing room, some left-handed and some right-handed,
- A TTY for use by people who are deaf to make phone calls from health care facilities,
- Staff awareness and training in using the National Telephone Relay System,
- Awareness and sensitivity training for all staff and professional personnel on interacting with people with disabilities.

The entire guide can be viewed at: http://www.fpg.unc.edu/~ncodh/rbar. By modeling programs on the recommendations in this guide, California could positively impact access for persons with disabilities.

In addition to environmental barriers, the Institute Of Medicine also found numerous barriers to health care transitions throughout the life span for people with disabilities, especially younger individuals. These include the fragmented organization of health care services, dysfunctional provider reimbursement methods, high levels of no insurance or incomplete insurance, limited sharing of information among generalists and specialists, and limited education of health care providers. The committee noted that health services researchers have tended to overlook people with disabilities and recommends that future efforts focus on the problems and needs of these individuals as they make transitions from early childhood, to school, to work, to older adulthood, and to retirement.

Telehealth/Telemedicine. In addition to environmental barriers which may impede access to health care facilities, many older adults and people with disabilities live in areas that are medically underserved. According to a report from the Office of Statewide Planning and Development (OSHPD), 49 of 58 counties in California have been identified as entirely or partially "medically underserved." (33) This means that those counties do not have sufficient numbers of primary care physicians at hospitals and other health facilities to meet the needs of the residents of these areas.

One way to address the issue of accessibility is through the use of telecommunication technology such as telemedicine and telehealth. Telemedicine is the use of electronic communication networks for the transmission of information and data related to the diagnosis and treatment of medical conditions. It has the potential of having a greater positive effect on the future of healthcare and medicine than any other modality, especially in rural, underserved or remote areas where it can bring high-quality care where

often little (or none) is available. Telehealth is the use of electronic communications networks for the transmission of information and data focused on health promotion, disease prevention, and the public's overall health including patient/community education and information, population-based data collection and management, and linkages for health care resources and referrals.

According to the OSHPD report, telecommunication technology is quickly expanding beyond hospitals to broader points of service in the public and private sectors, including home health, long-term care, and correctional facilities. Other sites, such as hospices and schools, are opportunities waiting to be explored. The data from surveys conducted among all three types of facilities indicate: (1) a need for education about telemedicine; (2) an overall lack of familiarity with or awareness of telemedicine; and (3) that implementation costs and lack of reimbursement for medical services are major issues when considering whether to develop a telemedicine program.

In 1996, the California Legislature passed the Telemedicine Development Act to lay policy groundwork for developing technology. The law has been updated a few times in an effort to keep up with new tools and new ways of doing things and a number of initiatives have been implemented to advance the use of telecommunications and health care technology. For example, see the California Telehealth Network at: http://www.caltelehealth.org/.

In an effort to stay current, a recent report, entitled "Advancing California's Leadership in Telehealth Policy: A Telehealth Model Statute & Other Policy Recommendations," has been issued by the Center for Connected Health Policy and is directed at legislators and policymakers. (34)

One of the report's main goals is to make telecommunication practices more widely available throughout California. The model statute report makes 13 recommendations in four categories:

- Revisions to the Telemedicine Development Act, focusing primarily on financial incentives and informed consent;
- Incorporating telehealth into state work force law;
- Statutory changes to promote interoperability of technology and consumer education; and
- Increasing research and education efforts in telehealth technologies.

Some of the report's recommendations include the following:

- Update the term "telemedicine" used in current law to "telehealth" to reflect changes in technologies, settings, and applications, for medical and other purposes;
- Require private health care payers and Medi-Cal—California's Medicaid program—to cover encounters between licensed health practitioners and enrollees irrespective of the setting of the enrollee and health care provider(s);
- Require the Office of Statewide Health Planning and Development to develop and implement a plan to provide greater visibility for the State Health Workforce Pilot Project, and require that OSHPD prioritize projects that utilize telehealth;
- Require state activities related to health information technology and health information exchange to explicitly include telehealth advocate representation;
- Require practitioners providing volunteer health services via telehealth to be included in any legislation that allows for malpractice coverage to volunteers providing health services; and
- Require malpractice insurance vendors and professional societies to educate practitioners regarding their options for malpractice coverage for telehealth services.

California AB 415, authored by Assembly Member Dan Logue and sponsored by the California State Rural Health Association, would update legal definitions of telehealth, streamline medical approval processes for the delivery of telehealth services, and modernize the state's health care system by broadening the types of telehealth services that can be provided. This bill is an important first step in laying the foundation for telehealth use in Medi-Cal and private insurance. For more information, view:
http://www.connectedhealthca.org/node/1282/

California is uniquely poised to exploit new technologies to address its health care needs because of its preeminence in the fields of telecommunications and information technology. Nevertheless, while significant advances in telecommunication have been made, much remains to be done to remove barriers to implementation and access, including the issue of malpractice as it relates to telehealth.

V. Financing Challenges and Barriers

If we look at the current profile of consumers of AT, a number of socio-economic challenges are apparent that will have implications for the future. In 2005, more than 4 million Californians were reported to be living in poverty. Close to 700,000 of these individuals had a disability and 146,999 had difficulty with self-care. (35)

As indicated earlier, the cost of many AT devices, especially the newer high-tech devices may be prohibitive for many people with disabilities and older adults 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.

Over the past few years, iDevices (iPads, etc.) and other PDAs and their applications are increasingly being used by people with disabilities and older adults. They can be especially helpful for people with vision, hearing, speech, mobility, learning and cognitive limitations. A growing number of state assistive technology lending programs, including California's AT Network Device Lending Library program (https://exchange.atnet.org/welcome.aspx), now offer several of these devices, and their popularity among consumers is increasing. But one major barrier to accessing and using these technologies is the lack of insurer coverage and other funding sources that could help consumers purchase and use these devices. This is especially problematic for low-income individuals who are living with disabilities but could benefit from the technology. One potential source of funding in California is the Change a Life Foundation (www.changealife.org). But overall, funding assistance is almost nonexistent at this point in time.

Older adults have the highest level of disability and are the major consumers of AT devices. However, despite the potential of AT to enhance independence and well-being, there are a number of discrepancies in usage, many based on socio-economic factors. For example, among a sample of frail older adults with hearing impairments, African-Americans were found to be much less likely to use hearing-related technology, including hearing aids, than their Caucasian counterparts. (36) Another study of older adults who have difficulties in activities of daily living revealed that African-Americans used fewer assistive devices than white participants, especially with regard to devices for hearing and vision. (37)

The California Study of Independent Living Centers revealed similar findings. (38) In the study, women were found to have greater overall usage of assistive devices than men. African-Americans and Latinos had lower levels of usage than whites, particularly of motorized or electronic devices, such as power wheelchairs or hearing aids and high-tech devices. Lower AT usage for medium- and high-tech devices was linked to lower levels of income and educational attainment. People with mental health disabilities, whose usage of any type of AT device was low, basically didn't use any high-tech devices. Those who could benefit from these devices might be forced to resort to more lower-tech devices that are either more affordable or easier to obtain through public programs.

Low levels of income, combined with high rates of disability, have significant implications for the use of AT, since people often pay for many AT and home accessibility features out of pocket. (39-40) For example, while home modifications have been shown to help achieve independence and reduce costs, both to individuals and the health care system, some of these modifications may be unaffordable to many individuals. The cost of home adaptations can range from a few hundred dollars to thousands of dollars, depending on the complexity of the technology. While there is a range of public and private financing sources available, these sources are far from comprehensive and eligibility requirements are often confusing, thus limiting access to those in need. (See Legal and Regulatory Challenges and Barriers page 32.)

Many organizations accept donated used assistive technology devices, including durable medical equipment and, after ensuring their usability, give them to new users under their 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. (See the CFILC AT Reuse Program here: http://atnet.org/resources/reuse-programs.php.)

Overall, one of the major barriers to the effective use of assistive technology, both in the United States and California, appears to be due to the fragmentation of the community service delivery system and its financing structures. Although several agencies provide assistive devices, or counseling or training on how to use them, or financing for them, the system does not appear to be well coordinated. While some people are able to obtain the AT devices they require and receive support on how to use them properly, in general, the delivery

system appears to be rife with confusion in coverage policies, gaps in service, and an overall lack of continuity.

Clearly, broad-based efforts need to be undertaken to improve the coverage of AT by both private and public insurers. If the future needs of Californians of all ages with disabilities 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. Several states across the country have instituted innovative reimbursement programs for a number of assistive technologies.

A study of 50 states conducted by the LeadingAge Center for Aging Services Technologies (CAST) revealed some exemplary financing programs that can provide guidance to California. "The report describes the availability of Medicaid Waiver reimbursement for Aging Services Technologies (ASTs) in each state. The analysis reveals that while the most common technologies reimbursed are Personal Emergency Response Systems (PERS) – 44 states reimburse for PERS– there are an increasing number of states that are providing reimbursement for other services, such as medication management (16 states)and telemonitoring/home telehealth (seven states). The report also shows that a couple of states have recently enacted policy change to add new reimbursement for ASTs while others are currently in such policy discussions. Pennsylvania has the most comprehensive coverage for ASTs in its Telecare program, including home telehealth, activity/wellness monitoring, medication dispensing and PERS, but New York, South Carolina, and South Dakota also have exemplary reimbursement programs. Read the complete report at: http://www.leadingage.org/uploadedFiles/Content/About/CAST/CAST_State_Paymen_%20Analysis.pdf. For more information on CAST go here: http://www.leadingage.org/.

Below is additional information on the Pennsylvania program. https://www.cms.gov/MedicaidStWaivProgDemoPGI/downloads/PA0279R0300.zip. A waiver from CMS enables the state to provide home and community-based services in concurrence with voluntary managed care including adult daily living services, home health care, respite, personal emergency response service (PERS), TeleCare, transportation, and specialized medical equipment and supplies.

VI. Legal and Regulatory Challenges and Barriers

Over the years, the federal government has taken a number of steps to make public spaces and buildings more accessible to people with disabilities. The Americans with Disabilities Act (ADA) of 1990 (and subsequent amendments), for example, prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities. The basic purpose of the ADA is to achieve the integration of persons with disabilities into all facets of society. (For a listing of federal laws and regulations pertaining to persons with disabilities go to http://www.ada.gov/cguide.htm. For state laws and regulations in California, go to http://www.disabilityaccessinfo.ca.gov/lawsregs.htm.)

Following enactment of the ADA, the Supreme Court issued the Olmstead v. L.C. decision in 1999. The Court held that the unjustified institutionalization of people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act (ADA). The Olmstead decision provides the opportunity to improve access to community-based care, prevent premature institutionalization and, in some cases, allow older adults who live in nursing homes to return to their communities. Despite the progress that has been made in the past few decades to enable people with disabilities across the country and in California to live independently, more work is required to meet the needs of older adults and people with disabilities. (41)

A state regulation related to health care reform that could affect the ability of persons with disability to live independently was recently enacted in California – the 1115 Waiver. An overview of what is covered in the 1115 Waiver renewal can be found at http://itup.org/pdfs/LA1115Waiver01-02.pdf. The intent of the 1115 Waiver is to expand health care coverage to low-income individuals and it authorizes mandatory enrollment of seniors and persons with disabilities into managed care. However, there is no mention of funding for assistive technology or home modifications. These issues, among others, have been raised by the disability community, especially advocates of the Olmstead decision. (See http://www.californiansforolmstead.org/site/c.ohLTJ3PIKqG/b.5958647/k.99CD/Waiver_Letter.htm.)

There is growing understanding of the benefits of enabling people with disabilities and health problems to remain in their homes as long as possible. At a Town Hall meeting in 2009, President Obama stressed the benefits of

home-based care in terms of its ability to keep older people out of more expensive institutional care and thereby control Medicare costs. (42) Also, the Department of Health and Human Services has incorporated the following goals into *Healthy People 2020*: 1) Increase the proportion of adults with disabilities who participate in social, recreational, community, and civic activities to the degree that they wish; and 2) Reduce the number of people with disabilities who report unmet need for assistive devices, service animals, technology services, and accessible technologies they need. (43)

Despite the growing support for AT, there is a long way to go. There are several sources of funding for AT, including Medicare and Medicaid (Medi-Cal in California), the Department of Veterans' Affairs, private insurance, some private and nonprofit organizations, and self-funding. Medicare and Medicaid, the biggest funders, cover assistive technology under their durable medical equipment (DME) benefit, but spending in this area accounts for only a small portion of overall program spending. For example, based on the 2001 Medicare Current Beneficiary Survey, it was found that 6.2% of beneficiaries obtained mobility assistive technology under the Medicare durable medical equipment (DME) benefit. These beneficiaries were disproportionately poor, disabled, and users of both acute and post-acute services. Average per item spending ranged from $52 for canes to $6,208 for power wheelchairs. Among beneficiaries who acquired such technology through the DME benefit, these devices comprised just 2% of overall Medicare spending. (44)

Medicare's narrow focus on restorative rather than compensatory care is a well-documented problem for people with chronic diseases and disabilities. (45) In essence, the coverage process undervalues many important services, such as assistive technology, where demonstrated evidence of their therapeutic effect is limited.

The National Council on Disability (NCD) recommends that the Centers for Medicare and Medicaid Services (CMS) should update its current definitions of durable medical equipment and medical necessity, which are outdated and give little consideration to increasing an individual's functional status. According to NCD, the current patchwork of federal and state health care and private insurance coverage contains barriers and gaps that leave many people with disabilities unable to obtain needed assistive technology. As a starting point, more consistent and coherent federal eligibility and reimbursement policies are needed. New definitions of medical necessity are needed to ensure that effective assistive technology is deemed eligible for coverage and

reimbursement. NCD also recommends that CMS identify and implement mechanisms to pay for assistive devices for people who are blind or have vision impairments who are beneficiaries of the Medicaid and Medicare programs or other federally subsidized health care. (46)

The Institute of Medicine (IOM) is another advocate for policy reform regarding AT and makes the following recommendations:

- A comprehensive disability monitoring system should be created to help monitor disability and inform policymakers. There should be more public funding for disability research programs.
- The Department of Justice should increase efforts to enhance the Americans with Disabilities Act, which will require health insurers to cover assistive technologies and devices.
- Congress and administrative agencies should eliminate long waiting periods for disability insurance.
- Consumers and professionals alike should be better educated about the proper care for people with disabilities and about the challenges they face. (47)

Unfortunately, the Medicare program doesn't seem to agree with the advocates for improvement in AT accessibility. The Centers for Medicare and Medicaid Services continues to advocate for policies and regulations that restrict patient access to medical equipment, such as power wheelchairs and oxygen, which is critical to allowing individuals to remain in their homes. Even the recently enacted healthcare reform legislation follows this trend by eliminating an option allowing a Medicare beneficiary to purchase a power wheelchair in the first month that the product is prescribed. In addition, the government has enacted a 36-month cap on oxygen reimbursement. The fundamental problem is that the CMS has sought to control Medicare costs by adopting policies and regulations that harm providers and slow expansion of the Medicare mobility benefits. (48)

The Department of Veterans' Affairs (VA) purchases more assistive devices for individuals with disabilities than most other agencies. Although a person must be eligible to receive VA benefits, VA is considered by many to be a model payment system. It has a systematized structure to pay for its large volume of equipment and it provides widespread education to consumers and clinical personnel. Furthermore, it also invests in research and development, evaluation, development of standards, and development of procurement

guidelines for assistive devices. The VA program covers traditional medical equipment such as artificial limbs and wheelchairs, as well as products that don't fall under the heading of "medical necessity" such as automobile and home modifications. (49) For information on the VA's coverage of DME, go here: http://www.va.gov/hac/factsheets/champva/FactSheet01-08.pdf. And for additional information and recommendations for access for veterans and AT, go here: http://www.atnet.org/law-advocacy/issues/at-and-vets.php.

In a survey of 359 U.S. manufacturers of AT conducted by the Bureau of Industry and Security, respondents expressed concerns about how cumbersome public and private insurance program participation procedures and outdated compensation methodologies may stifle innovation in new product development. (50) Because AT manufacturers are uncertain of when and under what reimbursement structure they will be permitted to sell their product, many product ideas remain on the shelf. The Bureau recommends that manufacturers of AT devices and interest groups representing people with disabilities need to work more closely with the state and federal governments to bring about changes in funding.

VII. Research Challenges

Due to the evolving nature of AT, more research is required in several areas. Data on AT need, use, and effectiveness in the United States are scarce. Unfortunately, people with disabilities have too often been overlooked by health researchers. If the needs of Californians with disabilities are to be adequately addressed across the lifespan, broad-based research efforts in a variety of areas need to be undertaken to achieve this goal.

Disability Trends. Significant variances in current disability data have been reported across the nation and in California as well. The 2000 US census estimates the number of persons with disabilities aged 5 and over in California to be 5.9 million, or about 19% of the population. (51) The *American Community Survey* for 2005, which excluded people living in institutions, estimates that more than 4 million Californians have at least one disability, or, approximately 13% of the population. (52) The 2007 *California Health Interview Survey,* a randomized telephone survey of non-institutionalized individuals, estimates the number to be closer to 8 million. (53) According to the Institute of Medicine (IOM), the major reasons for the variances are due to:

1) lack of consistent language used in surveys; and 2) inconsistency in the inclusion of all age groups and living situations. (54)

Just as we see variations in the monitoring of current disability data in the United States, we also find variations in the projection of future disability trends. An improved monitoring system is greatly needed if the needs of persons of all ages with disabilities are to be adequately met. The Institute of Medicine recommends adopting the *International Classification of Functioning, Disability and Health* (ICF) of the World Health Organization as the framework for disability monitoring and research. The ICF is based on a global consensus-building process that provides a standardized, internationally accepted language and conceptual framework to facilitate communication across national and disciplinary boundaries. For more information, see http://www.who.int/classifications/icf/en/.

By agreeing on and using comparable concepts and terminology to describe and measure different aspects of disability, the research findings would be more useful for decision makers. Furthermore, the committee recommends that data collection and monitoring cover individuals of all ages and in all living situations, including the community, group residential care settings, and institutions. In addition, surveys should provide information that can be used to monitor the incidence, prevalence, severity, and duration of the various components of disability.

Assistive Technology Use and Need. Assistive technology use and need in the United States today is difficult to estimate. Studies of AT usage, in general, are limited to a specific disability population, age group, or kind of technology that either control for the level of need or restrict the sample to a relatively homogenous disability population. (55) Based on surveys that have been undertaken, AT usage has been found to vary by such factors as age, gender, educational attainment, income, race, and ethnicity. (56-58)

Given the epidemiological trends in California, more research is warranted to better understand the functional and chronic illness needs of both current and future users of AT. More consistent and coordinated disability and AT monitoring in California is required to ensure that the needs of people with disabilities are adequately addressed. The Institute of Medicine found that health services researchers have tended to overlook people with disabilities. This omission also pertains to the need for AT. More research is required to identify the AT needs of individuals with disabilities and the barriers and problems they encounter as they make transitions throughout the lifespan. Clarifying

distinctions among trends in disease, functional limitations, and disability – and their interrelationships – will help policymakers and program officials anticipate the need for specialized medical care services such as assistive technology devices. (59)

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. According to the LeadingAge Center for Aging Services Technologies (CAST), the inability of different information systems to communicate with one another has slowed progress in creating an integrated, nationwide health information technology system. More research and development is warranted in this area to ensure the needed interoperability of devices. (60)

Involvement of Consumers and Other Stakeholders in AT Research, Design, and Evaluation. It is believed that proactive involvement of persons who use AT devices in their design and implementation will maximize the likelihood of their acceptance and continued successful use of the technology. (61) Also, it has been shown that an interdisciplinary approach to evaluation that involves all appropriate stakeholders, including consumers, caregivers, and health care providers, can reduce the risk of abandonment of AT devices. (62) Furthermore, many devices that have been developed have been limited to specific age groups. For example, most assistive technologies designed to address cognitive deficits were developed principally for younger persons with non-progressive traumatic or anoxic brain injuries, thus raising concerns about their generalizability to the progressive deficits associated with neurodegenerative dementias in older adults. Future research with assistive technologies needs to proactively involve age-appropriate participants in determining specific needs, device design and privacy preferences, as well as outcome evaluations. (63)

In several states, testing labs have been implemented that involve potential users and other stakeholders, including caregivers, health care providers, aging service providers, manufacturers, and engineers, among others, in the design and evaluation of assistive technology. For example, the Human Engineering Research Laboratories (HERL) at the University of Pittsburgh offers the following:

- Activities of Daily Living Laboratory
- Biomechanics and Neuromotor Control Laboratory

- Design and Prototyping Laboratory
- Electronics Laboratory
- Imaging/Modeling Laboratory
- Physiology Laboratory
- Robotics Laboratory
- Virtual Reality Laboratory
- Wheelchair Testing Laboratory
- Assistive Technology Evaluation Laboratory

For more information on the laboratories see http://www.herl.pitt.edu/.

The Age Lab developed at the Massachusetts Institute of Technology (MIT) involves a multi-disciplinary team of researchers, business partners, universities, and members of the aging community to design, develop and deploy AT innovations. (See http://agelab.mit.edu.) The MIT team examines the following:

- Effects of the physical environment on aging, e.g., home, stores, hospitals, automobile, community, airports, transit systems, consumer electronics, products and packaging, medical devices, mobile phones, furniture, etc.;
- How older adults allocate their attention, seek information and advice, and make sense, as well as choices, of important issues, e.g., health & wellness, financial planning, insurance, aging-in-place, long-term care options, end-of-life planning, major product purchases, etc.; and
- How business strategy and government policies affect older people and ultimately establish the context for society aging to be an opportunity or a burden.

The Center for Assistive Technology and Environmental Access (CATEA) at Georgia Tech is another example of a broad-based testing lab that involves a multidisciplinary team. CATEA's work is organized under four laboratories:

1. The Rehabilitation Engineering and Applied Research Laboratory (REAR Lab),
2. The Accessible Workplace Laboratory,
3. The Enabling Environments Laboratory (EE lab), and
4. The Accessible Education and Information Laboratory.

For more information, see http://www.catea.gatech.edu/about.php.

In California, an interdisciplinary CATLab (the California Assistive Technology Laboratory) is being developed at California State University, Fullerton. The lab includes gerontologists, sociologists and engineers working together to find solutions for the elderly who want to age in place. For more information, see http://www.fullerton.edu/initiatives/health and http://calstate.fullerton.edu/news/2009/026-assistive-technology-and-aging.html

The Mayo Clinic Center for Innovation in Rochester, MN has collaborated with the Center of Aging to establish a lab to support aging in place with new technologies. Other partners are Best Buy and WalMart. The program is called Healthy Aging and Independent Living lab (HAIL) and is similar to the CAT lab at CSU Fullerton. Read more at http://www.mayoclinic.org/news2011-rst/6311.html

To actively involve potential AT users, testing labs similar to the one being implemented at California State University, Fullerton and those created in other states could be developed across California. In addition to the labs cited above, examples of other AT testing laboratories can be viewed on the website of the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) and serve as models. For more information, see http://resna.org/atStandards/testing-laboratories.dot.

Outcomes Research. "Assistive technology outcomes" refers to what happens as a result of using an AT device or service. The "outcome" from the use of "AT" can cover a wide range of issues and goals, and could include whether:

- The technology was used or abandoned;
- The use of AT led to efficient completion of specific tasks/activities;
- The AT played a role in gainful employment;
- Cost savings were realized;
- Decreased family or caregiver support was realized;
- Increased independence resulted; or
- The individual's quality of life was enhanced.

(See Tech Connections AT Outcomes Measurement: http://smartech.gatech.edu/bitstream/handle/1853/26270/ATOutcomes.pdf;jsessionid=151873C82E5FA42750FBD155620D716A.smart2?sequence=1 and a consumer research study funded by United Healthcare:

Data on AT need, use, and effectiveness in the United States are scarce. (64) This is particularly true for California. Furthermore, due to the rapid advances in technology, the limited information that is available quickly becomes outdated.

Recent research has helped to quantify the value that some technology has to enhance independence and reduce costs. (65-66) However, many of these studies have been conducted on a small scale, leaving 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 has affected funding for AT. More large scale studies are needed to provide convincing evidence that specific technologies increase independence, enhance the quality of care, and lower health care costs. (67) Furthermore, it is believed that a stricter use of cost analysis methodologies should be implemented when researching the cost benefits of AT. (68)

In sum, additional research is required, both in California and the United States as a whole, to determine current usage of AT, attitudes towards AT, perceived obstacles to use, future needs, and benefits of AT. This research needs to be well coordinated, more consistent in terms of concepts and language, and include individuals of all age and ethnic/cultural groups and in all living conditions, as well as other private and public stakeholders. A comprehensive framework would be very useful in achieving this goal. One example is the Comprehensive Assistive Technology (CAT) model, developed in Scotland, which includes an ongoing dialogue among end-users, medical practitioners, clinical rehabilitation professionals, social support staff, and the engineering community. (69) Even though this model utilizes Scotland's comprehensive health care program which we do not have in the States, it is still a good model for what we might achieve here.

The Association of Assistive Technology Act Programs (ATAP) also provides a good overview of numerous initiatives that have been successfully implemented in various states across the country over the past decade to address a wide range of AT issues affecting all age groups. Based on these initiatives, advances have been made in the following areas: acquisition of new technology; training in specific areas of need; development of equipment loan programs and equipment

recycling programs; and access to accessible information technology. The initiatives are well coordinated and involve consumers, public and private organizations health care providers, and state agencies. These initiatives can serve as a good model for California in addressing a wide range of issues related to research and development, education, funding, policy, and legislation. Go to the ATAP website for more information: www.ataporg.org

APPENDIX

References

1) *State of Technology in Aging Services*, (2008) Center for Aging Services Technology (CAST)
http://www.aahsa.org/WorkArea/DownloadAsset.aspx?id=10729)

2) Kaye, H.S., (2000) *Computer and Internet Use Among People With Disabilities* (Disability Report No. 13), Washington, DC; U.S. Dept of Education, National Institute on Disability and Rehabilitation Research,
http://dsc.ucsf.edu/pdf/report13.pdf

3) Barrett, L. *Healthy@Home* (2008) AARP Knowledge Network,
http://assets.aarp.org/rgcenter/il/healthy_home.pdf

4) Institute of Medicine (IOM) (2007) *Health Care Transitions for Young People,* in The Future of Disability in America. Field, MS and Jette, AM eds. Washington, DC. National Academies Press, pp. 98-135.

5) Parette, H.P., et al. (2010) Supporting Families of Young Children with Disabilities Using Technology, *Education and Training in Autism and Developmental Disabilities,* 45(4), 552–565.
http://daddcec.org/Portals/0/CEC/Autism_Disabilities/Research/Publications/Education_Training_Development_Disabilities

6) Kintsch, A. and DePaula, R. (2002) *A Framework for the Adoption of Assistive Technology, Center for Lifelong Learning and Design*, Boulder, Co.

7) Elliot, R. (1992) *Assistive Technology for the Frail Elderly: An Introduction and Overview.* University of Pennsylvania.

8) Gallagher, E., et al (2002) *Laying the Groundwork for Improved Knowledge and Use of Assistive Devices Among Canadian Veterans and Seniors*, School of Nursing, University of Victoria, Victoria, BC., Canada.

9) Institute of Medicine (IOM) (2007) *Assistive and Mainstream Technologies for People With Disabilities* in The Future of Disability in America. Field, MS and Jette, AM eds. Washington, DC. National Academies Press, pp. 183-220.

10) Carlson, D., and Ehrlich, N. (2005) *Assistive Technology and Information Technology Use and Need by Persons With Disabilities in the United States, 2001*. U.S. Dept of Education, NIDRR.

11) Sheffield, M. (2005) *Assistive Technology Task Team Report to the California Commission on Aging*.

12) Gallagher, E., et al (2002) *Laying the Groundwork for Improved Knowledge and Use of Assistive Devices Among Canadian Veterans and Seniors,* School of Nursing, University of Victoria, Victoria, BC., Canada.

13) Ehrlich, NJ, et al (2003) Sources of information about how to obtain assistive technology: findings from a national survey of persons with disabilities, *Assistive Technology,* Summer, 15 (1); 28-38.

14) Institute of Medicine (IOM) (2007) *Assistive and Mainstream Technologies for People With Disabilities* in The Future of Disability in America. Field, MS and Jette, AM eds. Washington, DC. National Academies Press, pp. 183-220.

15) Pynoos J, Nishita CM (2007) *Aging in Place* in The Art of Aging Well: Lessons from Three Nations. Carmel S, Morse C, Torres-Gil F eds., Amityville, NY. Baywood Publishing Co., pp.185-198.

16) Kaye HS, Yeager P, Reed M (2008) Disparities in Usage of Assistive Technology Among People With Disabilities*, Assistive Technology* 20:194-203.

17) Ripple J, Stoddard S (2005) *California Statewide Independent Living Needs Assessment, 2003-2004*. Prepared for: California State Independent Living Council (SILC) and the Department of Rehabilitation, Sacramento, California. http://www.infouse.com/documents/SILCNeedsStudyReport.pdf

18) Pynoos J, Nishita M (2003) The Cost and Financing of Home Modifications in the United States. *Journal of Disability Policy Studies*. 14(2):68-73. http://dps.sagepub.com/content/14/2/68.short?rss=1&ssource=mfc

19) AARP (2000) Fixing to Stay, *A National Survey of Housing and Home Modification Issues*. Washington, D.C. http://assets.aarp.org/rgcenter/il/home_mod.pdf

20) *Department of Public Health, Los Angeles County Health Survey*, 2002-2003. Los Angeles, CA. http://www.publichealth.lacounty.gov/ha/hasurveyintro.htm

21) Pynoos J (2001) *Meeting the Needs of An Older Person to Age in Place: Findings and Recommendations for Action*. Resource Center for Supportive Housing and Modification, Univ of Southern California, Andrus Gerontology Center, Los Angeles, CA.
http://infoassist.panpha.org/docushare/dsweb/Get/Document-12020/Meeting%20the%20needs.pdf

22) Pynoos J, Nishita C, et al (2003) *Statement of Findings – Senior Related Housing Issues*. California Commission on Aging.
http://www.usc.edu/dept/gero/nrcshhm/research

23) Ripple J, Stoddard S (2005) *California Statewide Independent Living Needs Assessment, 2003-2004*. Prepared for: California State Independent Living Council (SILC) and the Department of Rehabilitation, Sacramento, California.
http://www.pascenter.org/reports/reports.php?focus=PAS%20Center%20Publications&project=workplace_pas

24) Wheaton L, Tochterman J (2009) *Aging in Place and Universal Design Resources.* Sacramento, CA, Department of Housing and Community Development - State of California.
http://www.hcd.ca.gov/hpd/aginginplace.pdf

25) National Resource Center on Supportive Housing and Home Modification (2003) *Home Modification* News (May).Univ of Southern California, Andrus Gerontology Center, Los Angeles, CA.
http://www.usc.edu/dept/gero/nrcshhm/newsletter/may03_index.htm

26) US Department of Health and Human Services (2005) *The Surgeon General's call to action to improve the health and wellness of persons with disabilities.* Washington, DC. US Department of Health and Human Services, Office of the Surgeon General.
http://www.surgeongeneral.gov/library/disabilities

27) US Department of Health and Human Services (2005) *Healthy People 2010*. Washington, DC. US Department of Health and Human Services.
http://www.health.gov/healthypeople

28) Institute of Medicine (2007) *The Environmental Context of Disability: The Case of Health Care Facilities* in The Future of Disability in America.

Field, MS and Jette, AM eds. Washington, DC. National Academies Press, pp. 162-182.

29) Jones, CA, et al. (2009) Health Status and Health Care Access of Farm and Rural Populations. *Economic Information Bulletin No. (EIB-57)*. http://www.ers.usda.gov/publications/eib57

30) Ramirez, et al. (2005) Disability and Preventive Cancer Screening; Results from the 2001 California Health Interview Survey. *Am J of Public Health* 95(11):2057-2064.

31) Markwalder, A (2005) *A Call to Action: A Guide for Managed Care Plans Serving Californians with Disabilities*. Disability Rights Activists, Oakland, CA. http://www.dralegal.org/publications/index.php

32) DeJong G, et al (2002) The organization and financing of health services for persons with disabilities. *Milbank Quarterly* 80(2); 261-301.

33) The California Telehealth/Telemedicine Coordination Project Planning Committee, *Final Report of the Telehealth/\Telemedicine Coordination Panel*, Office of Statewide Health Planning and Development (OSHPD. http://users.rcn.com/william.dnai/TH-TM-REPORT/sect1

34) Lauer, G. (2011) Keeping California in Front of the Telehealth Curve, *ihealthbea*t, http://www.ihealthbeat.org/features/2011/keeping-california-in-front-of-the-telehealth-curve.aspx#ixzz1IDDRoVmG

35) *American Community Survey for 2005*. Center for Personal Assistance Services (PAS), http://www.pascenter.org/home/index.php

36) Tomita, M.R., Mann, W.C., and Welch, T.R. (2001) Use of assistive devices to address hearing impairment by older persons with disabilities, *International Journal of Rehabilitation Research*, 24, 279-289.

37) Tomita, M.R., et al (1997) Racial differences of frail elders in assistive technology. *Assistive Technology*, 9, 140-141.

38) Kaye, H.S., Yeager, P. & Reed, M. (2008) Disparities in Usage of Assistive Technology Among People With Disabilities, *Assistive Technology,* 20:194-203.

39) LaPlante, MP, Hendershot, G. E., & Moss, A. J. (1997). The prevalence of need for assistive technology devices and home accessibility features. *Technology and Disability* 6, 17-28.

40) Carlson, D., and Ehrlich, N. (2005) *Assistive Technology and Information Technology Use and Need by Persons With Disabilities in the United States, 2001*. U.S. Dept of Education, NIDRR.

41) State Independent Living Council, (2010), *Needs Assessment for People Living With Disabilities*, Sacramento, CA., http://www.calsilc.org

42) *Medicare Policies Ignore Aging-at-Home Concept*, PR Newswire, http://www.prnewswire.com

43) *Healthy People 2020*, U.S. Dept of Health and Human Services, http://www.healthypeople.gov/hp2020/Objectives/TopicArea.aspx?id=17&TopicArea=Disability+and+Secondary+Conditions

44) Wolff, J., et al (2005) Wheelchairs, Walkers, and Canes – What Does Medicare Pay For and Who Benefits? *Health Affairs,* 24, no. 4: 1140-1149.

45) Anderson, G. and J. Knickman, J. (2001) Changing the Chronic Care System to Meet People's Needs, *Health Affairs* 20, no. 6: 146–160.

46) *Current State of Health Care for People With Disabilities*, (2009) National Council on Disability, http://www.ncd.gov

47) Fineberg, H. (2007) *Enabling People With Disabilities*. http://www.medscape.com/viewarticle/565110

48) *Medicare Policies Ignore Aging-at-Home Concept*, PR Newswire, http://www.prnewswire.com/

49) Elliot, R. (1992) *Assistive Technology for the Frail Elderly: An Introduction and Overview*. University of Pennsylvania.

50) *Technology Assessment of the U.S. Assistive Technology Industry*, (2003) Bureau of Industry and Security, U.S. Dept of Commerce.. http://www.icdr.us

51) Waldrop J, Stern S (2003) *Census 2000 Brief: Disability Status 2000*. U.S. Dept of Commerce, Economics and Statistics Admin, U.S. Census Bureau. http://www.census.gov/prod/2003pubs/c2kbr-17.pdf

52) Center for Personal Assistance Services (PAS) (2005) *American Community Survey for 2005*. http://www.pascentyer.org

53) UCLA Center for Health Policy Research (2007) *California Health Information Survey*. Los Angeles. http://www.chis@ucla.edu

54) Institute of Medicine (IOM) (2007) *Definition and Monitoring of Disability* in The Future of Disability in America. Field, MS and Jette, AM eds. Washington, DC. National Academies Press, pp. 35-64.

55) Kaye HS, Yeager P, Reed M. (2008) Disparities in Usage of Assistive Technology Among People With Disabilities*, Assistive Technology* 20:194-203.

56) LaPlante M, et al (1992) Assistive technology devices and home accessibility features; Prevalence, payment, need, and trends. *Advance Data.* Centers for Disease Control (CDC) 217:1-11. http://www.cdc.gov/nchs/data/ad/ad217.pdf

57) Russell JN, et al (1997) Trends and differential use of assistive technology devices in the United States, 1994, *Advance Data*. Centers for Disease Control (CDC) 292:1-9. http://www.ncbi.nlm.nih.gov/pubmed/10182811

58) Carrasquillo O, et al. (2000) Differences in functional status of Hispanic versus non-Hispanic White Elders: Data from the Medical Expenditure Panel Survey. *J of Aging and Health* 12:342-361.

59) *Trends, Research Brief* (2008), University of Michigan Center for the Demography of Aging, http://trends.psc.isr.umich.edu

60) *State of Technology in Aging Services*, (2008) Center for Aging Services Technology (CAST). http://www.aahsa.org/WorkArea/DownloadAsset.aspx?id=10729

61) Lehoux P, Blume S (2000) Technology assessment and the sociopolitics of health technologies*. J Health Polit Policy Law*. 25:1083-1120. Center for Aging Services Technology (CAST) (2008) *State of Technology in Aging Services*. http://www.aahsa.org/WorkArea/DownloadAsset.aspx?id=10729

62) Verza R, et al (2006) An interdisciplinary approach to evaluating the need for assistive technology reduces equipment abandonment. *Multiple Schlerosis* 12 (1): 88-93.

63) Bharucha A, et al (2009) Intelligent Assistive Technology Applications to Dementia Care: Current Capabilities, Limitations, and Future Challenges. *American J of Geriatric Psychiatry*. 17(2):88-104. http://findarticles.com/p/articles/mi_7449/is_200902/ai_n32315595

64) *Trends, Research Brief* (2008), University of Michigan Center for the Demography of Aging, http://trends.psc.isr.umich.edu

65) Verbrugge, L.M., et al (1997) The great efficacy of personal and equipment assistance in reducing disability. *American Journal of Public Health*, 87. 384-92

66) Hedman, G.(n.d.) *The Assistive Technology-Chicago Project Preliminary Cost/Benefit Analysis*, Assistive Technology Unit, Institute on Disability and Human Development, Univ of Illinois at Chicago.

67) *State of Technology in Aging Services*, (2008) Center for Aging Services Technology (CAST) http://www.aahsa.org/WorkArea/DownloadAsset.aspx?id=10729

68) Harris F, Sprigle S (2003) Cost analyses in assistive technology research. *Assistive Technology.* Summer;15(1):16-27.

69) Hersha, M, Johnson, M (2008) On Modelling Assistive Technology Systems. *Technology and Disability*. 20:193–215. http://www.elec.gla.ac.uk/assistive/media/cat_part1.pdf

CMS AT Competitive Bidding

On January 1, 2011, Medicare starts a new "competitive bidding" program for durable medical equipment and supplies in nine metropolitan regions: Charlotte, Cincinnati, Cleveland, Dallas-Fort Worth, Kansas City, Miami, Orlando, Pittsburgh, and Riverside, California. This program will affect thousands of Medicare beneficiaries who use the following equipment and related services and supplies: power wheelchairs, walkers, oxygen, CPAP and respiratory assistive devices, hospital beds, enteral nutrients (tube feeding), support surfaces, and mail-order diabetic supplies.

By design, this new Medicare program will severely restrict the number of companies that are allowed to provide the equipment and supplies listed above. While the program is supposed to help reduce spending in Medicare, it may result in increased spending at the emergency rooms and delayed transition from hospital care to home care.

More than 160 leading economists and auction experts, including two Nobel laureates, have warned that Medicare's bidding design for medical equipment will fail. Over the past two months, the experts have signed letters to congressional leaders criticizing the controversial bidding program.

The economic experts, who do not oppose the concept of using a competitive bidding system to set Medicare prices, found that this particular bidding program designed by CMS has alarming flaws that will prevent it from achieving its objectives of low cost and high quality home medical equipment and services for millions of seniors and people with disabilities across the country.

Bidders, the experts noted in their letters, are not bound by their bids, which undermines the credibility of the process. Additionally, the pricing rules encourage "low-ball bids" that will not allow for a sustainable process or healthy pool of equipment suppliers. Ultimately, the bid design provides "strong incentives to distort bids away from [actual] costs," and lacks transparency that is "unacceptable in a government auction and is in sharp contrast to well-run government auctions."

The economic experts' letter concludes, "This collection of problems suggests that the program over time may degenerate into a 'race to the bottom' in which suppliers become increasingly unreliable, product and service quality deteriorates, and supply shortages become common. Contract enforcement

would become increasingly difficult and fraud and abuse would grow…
Implementation of the current design will result in a failed government
program."

Also opposing the controversial bidding program are a bipartisan group of 257
members of Congress and more than a dozen national consumer and patient
advocacy groups. Those consumer groups include the ALS Association,
American Association of People with Disabilities, Muscular Dystrophy
Association, National Council on Independent Living, National Spinal Cord
Injury Association, and United Spinal Association.

<div align="right">June 13, 2011</div>