

# The Promise of Technology as a Caregiving Resource: *Supplementing ElderCare with ElderTech*

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Presentation to Administration on Aging Conference on  
The National Family Caregiver Support Program:  
“From Enactment to Action”  
September 7, 2001

## I. INTRODUCTION – THE CHALLENGES OF ELDERCARE IN THE 21<sup>ST</sup> CENTURY

A. **Defining the Problem --** The demand for caregiving and long-term care services and environmental supports is increasing at the same time the supply of informal caregivers is shrinking and the cost of providing personal care is increasing.

### B. **Demographic Factors Contributing to Increased Demand & Reduced Supply**

- **Longevity Revolution:** Due to increased life expectancy and declining birth rates, individuals are living longer and the proportion of the population 65+ is increasing dramatically, contributing to “population aging” (result = increased demand for caregiving & personal assistance services or PAS).
- **Aging and Disability:** Despite dramatic improvements in health, aging is strongly correlated with the onset of disability. The “good news” is that people of all ages with disabilities are surviving long enough to experience both the rewards and challenges of increased longevity. This means that for the first time in history, significant numbers of people are “aging *with* disabilities” acquired at different stages of the life course – i.e., those “aging with long-term disabilities” acquired in childhood and young-adulthood and those “aging *into* disability” for the first time in later life due to age-related chronic diseases, many of which were once considered terminal diagnoses (result = increased demand for caregiving & PAS).
- **Changing Demographics of Disability:** Together, the dual trends of increased survivorship and increased longevity are changing the demographics of disability. Once thought to be a “problem” affecting a small segment of the population, persons of all ages with functional and activity limitations due to physical, sensory, emotional, and/or cognitive impairments now represent the largest “minority group” in America, numbering approximately 50 million or 15% of the total population (result= increased demand for caregiving & PAS).

- **Changing Structure of Families:** Declining fertility and smaller families, combined with historic shifts in the labor force participation of women and high rates of geographic mobility and divorce and remarriage, have reduced the availability of family caregivers. A situation that is expected to worsen in the next two decades with the aging of the Baby Boomers. Nevertheless, at the present time, 73% of persons 65+ with chronic disabilities rely exclusively on informal caregivers.

C. **The Net Result -- “The Paradox of Longevity”**

Increased life expectancy is one of the greatest achievements of the 20<sup>th</sup> Century. We have invested billions of dollars to bring about this result through improved healthcare delivery, medicine, medical technology, nutrition, and even physical fitness campaigns. The paradox lies in the fact that less thought and resources have been given to figuring out what individuals, and society as a whole, might require if our investments in longevity actually succeeded (Joseph Coughlin, MIT). The net result is that we are living longer, but are less prepared to meet the needs of an aging society for the types of services & supportive environments that “add life to years.”

II. **THE PROMISE & REALITY OF TECHNOLOGY AS A CAREGIVING RESOURCE**

A. **The Technology Revolution & Promise**

A parallel development of equal significance to the demographic revolution of the post-WWII era is the rapidly progressing “technology revolution” of recent years. In a very short period of time, applications of technology have produced profound changes in every aspect of the way we live, work, learn, communicate, shop, and receive and deliver services. Established technologies also have impacted the lives and independence of people with disabilities, although the benefits have not been equally distributed across the age range. Moreover, recent advances in computer and information technologies hold even more promise to open new frontiers for this segment of the population and their care providers. For example, technology can help people with disabilities and their care providers: better monitor their health and nutrition; remain in their own homes; travel more freely about the community or in some cases drive a care; use a telephone and communicate more easily; leave the house without having to rely on the help of another person; take care of personal needs independently; engage in lifelong learning and participate meaningfully in family and community activities.

In sum, technology has the potential to serve as a powerful resource in meeting the needs of caregivers by supplementing more traditional personal assistance services with “ElderTech.” But, the promise of technology also extends further to promoting “successful aging,” in general, and thereby reducing the demands for caregiving.

Examples of “ElderTech” or “technologies for successful aging” include the following:

- Assistive technologies to aid functional capacities of individuals – i.e., sensory, mobility, manipulation, and cognition
- Information & Wireless Technologies – e.g., computers & other devices  
IT is an important element in both home-based monitoring systems and the creation of “smart environments” that improve health and safety and support communication and social integration.
- Telecommunication Technologies
- Consumer Products & Safety
- Transportation
- Environmental interventions and home modifications

**B. The Digital Divide & Barriers to Technology Access & Use**

But the promise of technology, new or old, for people with disabilities is not matched by the reality. Assistive technologies of all types are used by only a small fraction of the disabled population who might benefit from them. Many people with disabilities lack even the more affordable, lower-tech devices that could help them function, such as manual wheelchairs and hearing aids. They are also less likely to be aware of what technology is available and of its potential benefits.

The gap between “needs” and “use” is even greater for computer and information technologies, where it is safe to say the vast majority of Americans with disabilities have been left behind. In general, people of all ages with disabilities are half as likely as their non-disabled counterparts (32.6% vs. 55.6%) to own a computer and only one-quarter as likely to use the Internet (15.1% vs. 42.3%). But, the situation is even more pronounced for the elderly with disabilities. Within this segment of the disabled population, only 10.6% have a computer compared to 25.3% of their non-disabled same-aged cohorts and the number reduces to 2.2% compared to 8.9% for Internet use. Race/ethnicity and family income also affect access to computer technologies.

The net result of this “digital divide” is that many elderly people with disabilities and their caregivers lead more restrictive and stressful lives than their more affluent and non-disabled counterparts. In sum, technology constitutes a powerful but underutilized resource in our national efforts to support caregivers and “add life to years”.

Factors contributing to the underutilization of technology among the elderly include:

- Lack of investment in research and development to stimulate applications of “elder-friendly” technology for the older market

## Outline of Presentation to AoA Conference on NFCSP: Technology as a Caregiving Resource

- Lack of emphasis on technology transfer from federally developed technologies to assistive technology industries for the elderly
- Lack of accessible information technology (inaccessible hardware and software) and lack of simplified interfaces
- Lack of communication and coordination among government-funded agencies and programs (e.g., AoA and NIDRR), private companies, and interest/advocacy groups (e.g., National Council on Disability & AARP).
- Lack of affordability of many assistive and information technologies and lack of meaningful insurance reimbursement. Although the cost of some technology has come down in recent years, assistive technology can still be prohibitively expensive for many people with disabilities, especially those on fixed incomes like the elderly and their caregivers. And, as the sophistication of the technology increases so does the cost. For example, a computer good enough to run the best speech recognition, speech synthesis, and speech reading or screen magnification programs can cost \$2,000 plus \$500 to \$1000 for each program. A closed-circuit television costs between \$2,000 and \$3,000, as does a simple assistive communication device that speaks synthesized messages upon demand. A scooter costs approximately \$3,000 versus \$10,000 for a custom power wheelchair; and a new accessible van to transport the scooter or power W/C can cost as much as \$40,000.
- Societal attitudes toward aging and disability that favor medical treatments and traditional long-term care services over technology and environmental interventions and supports.
- Lack of technological sophistication and low education/awareness of the benefits of technology among both the elderly and their service providers.
- Lack of training among service providers in assistive technology developments and applications.
- Lack of a comprehensive and coherent system of caregiver support programs due, in part, to substantial variation in eligibility from state to state based on diagnosis or functional level of impairment (e.g., Alzheimer's vs. developmental disability), age, and income.
- Lack of integration among state caregiver support and technology assistance programs and the traditional separation of funding and delivery systems between health care and social services. The healthcare system has restricted access to assistive technologies by limiting coverage to those devices that meet the criterion of "medical necessity" rather than "functional necessity." Similarly the social service system has limited access to technologies for successful aging by funding primarily personal assistance. For example, state funded-caregiver support services programs, such as the California Caregiver

Resource Centers, have few or no linkages to the state-run Technology Assistance programs or TAPs.

**D. Overcoming the Divide Between Personal assistance & Assistive Technology**

For too long, both health care providers and members of the “aging services network” have treated assistive technologies and personal assistance services/caregiving as mutually exclusive resources.

In contrast, the author argues that “technologies for successful aging” are consistent with the goals of the new NFCSP to promote self-determination and consumer direction and with the principles of systems change, which include: family role, access, coordination, choice, diversity, participation, respect, and accountability.

**III. THE BUILDING BLOCKS OF A TECHNOLOGY FRAMEWORK TO SUPPORT ELDERCARE & SUCCESSFUL AGING**

**A. The ElderTech Effort**

- Definition – “ElderTech refers to ways elderly people and their care providers can employ assistive and information technologies to enhance health, independence, and community integration (Joshua Charm, 2000).
- Building on the Technology Act of 1988 & 1994, and the Technology Transfer Act of 1997, the “ElderTech” term originated in 1999 as a policy initiative of the Clinton Administration designed to establish a sustained and long-term federal investment in research and development to promote age-friendly technologies and environments.
- Goals of the ElderTech effort were to (1) establish a technology framework that will assure the U.S. is ready to meet the needs of its older Americans and (2) assuage some of the financial pressures on Medicare & Medicaid.
- Within the ElderTech effort, assistive technology is seen as “the key to independence.” Assistive technology is defined as any item, piece of equipment, or product system that can be used to maintain or improve the functional abilities of an individual. Assistive technologies can be simple devices, such as canes and walkers, and low technologies, such as hearing aids and communication boards. Or, complex technologies such as computer-based text readers and speech synthesizers, or “Smart Homes” and “lifelong transportation’ systems.
- The ElderTech effort of the Clinton Administration culminated in a White House Office of Science and Technology Policy (OSTP) sponsored conference on “Technologies for Successful Aging” in October, 2000 (see

distributed proceedings). Both AoA and NIDRR, my agency, along with the Veterans administration were co-sponsors of this two-day event.

**B. Recent Complementary Policy Initiatives**

- **National Family Caregiver Support Program (NFCSP)** – Enacted as part of the Older Americans Act of 2000 (Public Law 106-501), builds on the Family and Medical Leave Act of 1993 to recognize that families, not social service agencies, nursing homes or government programs, are the mainstay underpinning long-term care for older Americans in the United States. Funded at approximately \$125 million in fiscal year 2001, the program calls for all states, working in partnership with area agencies on aging and local community-service providers to have five basic services for family caregivers, including:
  - Information about available services
  - Assistance to caregivers in gaining access to services
  - Individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions
  - Respite care for caregivers, and
  - **Supplemental services, on a limited basis, to complement the care provided by caregivers – e.g., “ElderTech.”**
  
- **The Bush Administration’s New Freedom Initiative for People with Disabilities:** The goal is to increase Federal investment in assistive technology research and development as a means of fulfilling the ADA and improving the lives of persons with disabilities. Specific objectives of the initiative, many of which are compatible with the concept of “technology for successful aging,” include:
  - Increasing Access to Assistive and Universally Designed Technology
  - Expanding Educational Opportunities,
  - Integrating Americans with Disabilities into the Workforce, and Promoting Full Access to Community Life
  
- **Executive Order #13217: Community-Based Alternatives for Individuals with Disabilities.** Signed on June 18, 2001, the order “calls for the swift implementation of the Supreme Court’s Olmstead decision that holds that unjustified isolation or segregation of qualified individuals through institutionalization is a form of disability-based discrimination prohibited by Title II of the ADA.” The order is described as “exemplifying the Bush Administrations commitment to a federal role that fully advances the ability of all people with disabilities to live and participate in their communities.”

**C. Examples of Government Agencies & Organizations Involved in Research & Development Activity & Technology Transfer**

- National Institute on Disability and Rehabilitation Research (NIDRR), located in the U.S. Department of Education, has a long-term research agenda aimed at promoting “technology for function and access.” In addition to managing the state Technology Assistance Programs, NIDRR funds its technology agenda through several mechanisms, including Rehabilitation Engineering Research Centers. Under this category, NIDRR is currently competing new priority for \$4.5 million Research and Training Center on “Technologies for Successful Aging” (to be awarded 10-1-01). This center will stimulate R & D activity in home-health and monitoring technologies and personal communication technologies, such as Smart Phone. (for NIDRR web-site see: <http://www.ed.gov/offices/OSERS/NIDRR/>)
- The Rehabilitation Research and Development division of the Veteran’s Administration funds “Centers of Excellence,” in particular areas such as geriatric rehabilitation and aging with a disability.
- National Institutes on Aging funds Centers for Research on Applied Gerontology.
- Federal Lab Consortium on Technology Transfer (FLC) and NASA’s National and Regional Technology Transfer centers (NTTC & RTTC), including the Mid-Atlantic Technology Applications Center in Pittsburgh, which works with U.S. firms to assist them in the assessment, acquisition, utilization, and commercialization of technologies and expertise from the federal laboratory system.
- In the European Union, the community Technology Initiative for Disabled and Elderly (TIDE) program, which works to serve the technology needs of both the disabled and elderly.

**D. Organizations & Conferences Promoting “ElderTech”**

- Johns Hopkins University Conference on “Aging and Associated Disability in the Information Age” (June, 2001)
- International Conference on Technology and Aging (ICTA), Toronto Convention Centre, Ontario, Canada, September 12-14, 2001. Described as a ICTA revolution, this conference attempts to reach out and include designers, researchers, policy makers, senior consumers, industry representatives, and caregivers or operators of homecare programs (<http://www.icta.on.ca/English>)

IV. PROMISING PRODUCTS & PRELIMINARY APPLICATIONS OF ElderTech

**For a comprehensive resource of both Information and Assistive Technology products, see the award-winning ABLEDATA web-site, sponsored by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education <http://www.abledata.com/>**

**A. Examples of Promising Assistive Technologies to Maintain Function by Type of Impairment Prevalent Among the Elderly**

1. Visual Impairment – According to data from the 1994-95 NHIS on Disability, a sizable number of the 6.4 million Americans who are blind (1.1 million) or have significant visual impairments (defined as “serious difficulty seeing, even when wearing glasses or contact lens) would benefit from the kinds of assistive technology that are currently available or are expected to become available in the near future. These include:
  - Talking computers, which use special devices to translate text on the screen into spoken words.
  - Talking signs – an information system that promises to greatly increase the ability of blind people to find their way through a confusing urban environment. Small, unobtrusive infrared transmitters are attached to the pedestrian signals at crosswalks, to bus kiosks and subway platforms, to buildings, and to rooms, elevators, and stairways within buildings. Carrying a handheld receiver about the size of a TV remote control, users hear short messages conveying “signage” information, such as “traveling north on Polk Street, etc. About 900 Talking Signs are currently in operation in San Francisco, and interest in this technology is likely to increase significantly with the passage in 1998 of the Transportation Equity Act, which encourages audible signs and traffic signals at intersections.
  - The problem is that only about 20% of people who are blind and 4% of people with other serious visual impairment use any kind of assistive technology.
2. Hearing Impairments – A new and important development in this area is a device known as an “Interactive Pager.” Supplemented with services for deaf and hard-of-hearing customers, this technology allows wireless two-way communication via typed-in text messages. In effect, creating the equivalent of a mobile phone for this community.
  - Other technologies of particular benefit to the hearing impaired include closed-captioned television and electronic email and instant messaging.

- However, even among the deaf, less than half (44%) use any kind of assistive technology and most of that are hearing aids. Less than 15% of the deaf and hard-of-hearing community use TDDs and closed-caption TVs.
3. Mobility Impairments – According to the NHIS-Disability Survey, approximately 16.6 million Americans have some degree of limitation in their ability to walk, and 10.0 million have significant mobility impairment, with 5.4 million being unable to walk one-quarter of a mile or climb 10 stairs. Of this segment of the population only 6.8 million use any assistive technology to help them, and then it is likely to be a low-tech aid such as a cane, walker or manual wheelchair (1.5 million Americans, 57% of whom are elderly).
- It seems likely that many users of manual wheelchairs, particularly those with the leading causes severe mobility impairment – namely arthritis, stroke, and multiple sclerosis, would achieve far greater independence through use of motorized devices. Yet, only 155,000 of the total number of mobility-impaired individuals use an electric wheelchair and only 140,000 use scooters. And, as with most assistive technologies, the elderly are significantly less likely to use these higher-tech devices than their non-elderly counterparts (62% vs. 38%).
  - Despite these low utilization rates, a new super-high-tech wheelchair is soon to be made available by Johnson & Johnson. The IBOT can traverse sand, grass, and dirt, and rotate up and down to easily climb over a curb or up and down stairs. It can also raise the user up to a standing position to shake a person’s hand, take dishes off the top shelf or dress one’s self. The problem is price. The IBOT is expected to sell for \$20,000 to \$25,000.
4. Difficulty Communicating – Some 1.7 million American have difficulty communicating their thoughts and needs to others. And, of these, 650,000 have trouble communicating even with other family members. A great variety of low-tech and high-tech tools exist to assist communication, yet like other types of assistive technologies few persons with communication disorders take advantage of these devices. Examples of new high-tech communication devices in the test stage include:
- Honeywell’s Independent LifeStyle Assistance device (ILSA), and
  - Motorola’s “Smart Phone”

**B. Selected Demonstration Research Projects**

- Telemedicine & Home-Based Monitoring -- Telemedicine Network of Northeast Maine –innovative approach for homebound elders. Visiting Nurses Associations collaborated to bring health care directly into elders’ homes (via videophone) to relieve burden on caregivers and provide better coordination

of services. Documented benefits include improved frequency and quality of communications between nurses and patient, increased consumer education, and reduction in number of inpatient days in hospital. Currently developing third tier of program to allow triage nurses to be on call for home care agencies after hours. This will also give patients access to a clinician through videophone 24 hours/day.

- “Lifelong Transportation” – the U.S. Dept. of Transportation is actively looking into safe transportation for an aging society. Many performance-aiding technologies will become available in the coming years to enhance the safety and ease of operating vehicles for the elderly with disabilities and their caregivers. Some of the most promising of these “Intelligent Transportation Systems” are the Collision Warning/Avoidance Systems, In-Vehicle Signing, and Rural Public Transportation Systems.
- “The Aware Home of the Future,” – Researchers at the Georgia Institute of Technology, and those at other institutions, are building so called “smart homes” as living laboratories in which to develop and test environments where computers are constantly present and seamlessly integrated into the “woodwork” to support “aging-in-place” and the everyday activities of future cohorts of older adults and their caregivers. (For details see the following Web site: <http://www.cc.gatech.edu/fce/ahri/> ).

### **C. Programs & Partners in Promoting Technology as a Caregiving Resource**

State Technology Assistance Programs –funded under the Technology-related Assistance for Individuals with Disabilities Act (the “Tech Act”) provide the infrastructure to deliver assistive technologies to the disabled community. They offer help to consumers in selecting appropriate devices and training in how to use them. They also provide assistance in how to purchase AT, including information on public programs and loans to finance acquisition.

## **V. NEXT STEPS IN PROMOTING ELDERTECH AS A CAREGIVER RESOURCE**

- A. **Goal --** People of all ages with disabilities and their care providers are perhaps the single segment of society with the most to gain from increased access to and utilization of both established “low-tech” devices and the new technologies of the electronic age – namely computers, the Internet, and high-tech assistive devices. They stand to benefit in terms of increased health and independence, community integration and social participation. And, yet their utilization rates lag behind all other segments of the population.

Therefore, the goal of the “ElderTech revolution” is to create age-friendly technologies and environments to support caregivers and reduce the demand for caregiving.

- B. **Suggested Strategy to Advance the “ElderTech Revolution”** – Need a Presidential Initiative on ElderTech that combines features of the NFCSP, the New Freedom Initiative for People with Disabilities, and the recent Executive Order #13217 regarding Community-Based Alternatives for Individuals with Disabilities to accomplish the following.
- Merge AAAs and state aging programs (SAPs) with state Tech Act programs (TAPs) to eliminate duplication of service systems and facilitate information dissemination and technical assistance about ElderTech to persons of all ages with disabilities.
  - Increase investment in Research & Development to stimulate accessible products and information technologies
  - Increase capacity building by providing more and better training on TSA to healthcare workers and members of the aging network
  - Create distance and e-learning Systems for older Americans – those with and without disabilities-- and provide Email assistance online and Web-based training and mentoring
  - Increase public funding (SSDI, SSI, Medicare & Medicaid) and private insurance coverage and remove programmatic barriers among public funding programs (SSDI, SSI, Medicare, Medicaid, State Technology Assistance (Tech Act) Programs) to ensure “technology equity” among all segments of the population.
  - Increase public awareness & knowledge of TSA applications and solutions
  - Increase access to TSA by and for elders
  - Increase utilization of TSA by elders and their care providers and case managers