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The Potential for Technology to Enhance Independence for Those Aging with a Disability

Abstract

Technologies of all kinds can sustain and accelerate improvements in health and quality of life for an aging population, and enhance the independence of persons with disabilities. Assistive technologies are widely used to promote independent functioning, but the aging of users and their devices produces unique challenges to individuals, their families, and the health care system. The emergence of new "smart" technologies that integrate information technology with assistive technologies has opened a portal to the development of increasingly powerful, individualized tools to assist individuals with disabilities to meet their needs. Yet, issues of access and usability remain to be solved for their usefulness to be fully realized. New cohorts aging with disabilities will have more resources and more experience with integrated technologies than current elders. Attention to technological solutions that help them adapt to the challenges of later life is needed to improve quality of life for those living long lives with disabilities.

Keywords

Assistive Technology; Aging; Internet

Introduction

A recent IOM report on the Future of Disability in America states that "designing technologies today for an accessible tomorrow should be a national priority."[1] National goals of accessibility and equality for persons with disabilities can best and most cost-effectively be achieved by leveraging the potential of both assistive and mainstream technologies for independent living. In Healthy People 2020, the US Centers for Disease Control prioritizes environmental accessibility, universal design and reduction of barriers to assistive devices and technologies in order to improve participation by people with disabilities in work, education, and social activities.[2] These priorities stem from our belief that increasing the independence of persons with disabilities (at all ages) will not only benefit the individual, but also will benefit society by reducing health care and formal long

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term care expenditures, dependence on family members and other informal supports, and harnessing the productive activities of those who are underemployed.

Using disability as an umbrella term for a large and diverse population with varied needs creates additional challenges to realizing the development and implementation of technological solutions for persons with disabilities. Attention has been paid most often to specific patient populations in clinical settings or to those that share similar conditions, such as developmental disabilities, sensory impairments, or motor impairments, and tends to focus on immediate solutions to needs. Long range planning is infrequent, even where progressive trajectories of impairment are expected.

This approach stands in contrast to the rising number of young persons who carry early life disabilities into later life. Life expectancy remains shorter for persons with developmental disabilities, childhood injuries, and diseases (e.g. polio or cerebral palsy) than the rest of the population, but maximum lifespan among these individuals appears to be rising and a growing number of these persons may live long enough to experience the consequences both of aging and of long term disability.[3-5] Injuries and other sources of adult onset disability also tend to have less impact on survival, and these individuals frequently experience symptoms of premature aging.[6-7]

Studies of trajectories of specific early life conditions reveal that individuals with early and mid-life disability experience initial declines in ability, followed by a pattern of improvement and stability, followed by additional functional problems.[4] Yet, there is a large gap in research on the transition to adulthood for those with developmental and other childhood disabilities and on trajectories of disability through adulthood, perhaps because of the perception that adulthood is a period of stability in health. More evidence is available about those that reach the oldest ages than about the intervening years. Understanding the opportunities for intervention during critical periods that influence successful aging with a disability requires investing in a life course perspective on the health changes, economic resources, family support, and individual accommodations that affect the aging of individuals with disabilities.

This paper reviews current knowledge about the use of assistive devices and the emerging role of information technology in the lives of persons living with disabilities, and identifies issues related to the integration of technologies into policy and planning for successful adaptation to aging with a disability.

Technology and Disability: tools for individuals aging with disability

The improved survival to and through older ages that characterized global advancements in health in the last century launched a long and robust research and policy agenda designed to sustain and accelerate improvements in health and quality of life for aging populations. Technology embodies great promise to provide the tools to accomplish these goals from the level of the individual up to the health system.

Broadly speaking, technology is “the systematic application of scientific or other organized knowledge to practical tasks.[8]” Considered as such, all of the ways that people with

disabilities adapt to the challenges of their environment might be considered “technological solutions.” However, more commonly technological solutions for those with disabilities refer to assistive technology, a highly varied class of devices and systems that includes both commercially developed or purpose-built devices that are designed to assist with specific tasks; or mainstream technologies, which serve to make life easier for everyone, but may be particularly useful for persons with specific challenges in day to day functioning.

In real life, individuals invent an infinite number of ingenuous accommodations that make use of existing tools and equipment in new ways. Norman Kunc has written about his life with cerebral palsy and the pride he feels in developing solutions such as “knowing which cup fits snugly into the sink drain and doesn’t tip over when I pour coffee.”[9] In the absence of professional help, people tackle the tasks before them with astonishing creativity, but they equally often may be stymied by the most basic barriers. In a recent study in East Baltimore, an older woman with mobility problems was stopped from leaving her house by marble entrance steps which had no railing. For liability reasons, the transit service picking her up could not assist her down her stairs. [10]

A related distinction in the development of technological assistance for disabilities is the difference between universal design and assistive devices/environmental modifications. Advocates of universal design promote the benefits of standardizing devices and environments so that they are uniformly accessible or usable by persons of varying abilities. While universal design is a beneficial principle by which to develop general guidelines for construction and product development (e.g. railings for stairs), there is also a growing movement in public health towards interventions tailored to individuals with specific constellations of needs.[11] In this way, the relationship of individual capacity to the physical environment can be taken into account in developing customized solutions. Such an approach is a beneficial complement to universal design and may be an important bridging step in responding to the increasing complexity of needs among persons aging with disabilities, especially given how little is known about the typical pathways of health change that these individuals experience (to the extent that there are typical patterns).

Use of Assistive Technology among those with early and mid-life disabilities

In studies of disability at older ages, advancements have been made in understanding use of assistive technology, though little study has been given to the subgroup of persons aging with lifelong or long-term disabilities. Moreover, relatively little is known about the prevalence of assistive technology use among younger adults living with disabilities. Population level statistics on use and access to technologies for disability are limited and old. Surveys in the 1990s showed that prevalence of assistive technology use among adults with disabilities is high and use of multiple devices is common. Assistive technology use rises with age,[12] but this is likely due to the greater prevalence of disability in the older population. Despite the fact that most disabilities experienced in old age are acquired later in life, a survey of clients for the California Independent Living Centers (ILCs) found that birth onset of disability was a highly significant predictor of both the use of any assistive technology and the number of devices used. [13]

For children and adolescents, the 1994 U.S. National Health Interview Survey Supplement on Disability (NHIS-D) reported that almost 25% of children and adolescents with disabilities used assistive devices.[14] The school-based National Longitudinal Transition Studies (NLTS-1 & 2) estimated that between 20% and 35% of students with disabilities use some form of assistive technology, and students with visual impairments had the highest prevalence of use. [15]

Use of assistive technology appears to be less common for those with intellectual disabilities: a national survey of adults with intellectual disabilities reported only 10% of individuals with mental retardation use assistive devices and the prevalence is lower than for those with physical disabilities. [15] The California ILC study also showed that adults with mental health disabilities are significantly less likely to use assistive devices, and use fewer devices, controlling for a large number of covariates.[16] These reports are similar to findings for the older population showing that cognitive impairment limits the capacity of individuals to use assistive technology on their own.[17]

Benefits of assistive technology

The limited availability of statistics on assistive technology use make it difficult to estimate prevalence of device use among adults aging with disabilities and to quantify levels of unmet needs. However, there is evidence of the benefits of assistive technology. Older assistive technology users report greater reductions of difficulty than those relying only on personal care[18-20] and experience delays in functional decline. [21-23] Slower functional declines in associated with device provision also have been suggested by small scale studies of persons aging with disabilities.[7] Mobility devices in particular have been found both to improve ambulation and to increase feelings of security, though misuse can place users at risk of falling.[23] Mobility devices also appear to improve the experience of informal caregivers, who benefit from relief of some of the physical demands of care, as well as the additional security devices provide.[24]

Devices also improve well-being by promoting independence. The use of assistive technology enhances the ability of adults to make choices about when and how they carry out activities and improves participation.[25] A long term study of spinal cord injury showed that independent wheelchair users reported fewer depressive symptoms and higher levels of social participation than those who were dependent in ambulation or dependent in wheelchair use, implying that independence of action is an important contribution of technology to successful aging with a disability.[26] The independent use of assistive technology is particularly important for those aging with developmental disabilities, many of whom live with family members or in group settings. The use of assistive technology has been associated with better functioning among adults with developmental disabilities transitioning from residential care to the community,[27] but overprotective caregivers can undermine the opportunity to conduct tasks independently, and encouraging cooperation of helpers to allow independence is also important[28-29]

Long term use of assistive technologies

Persons aging with disabilities are likely to have been using assistive technologies for many years. Over time, users identify the devices that work best for them and become familiar with and skillful at using their equipment. However, the mechanics of activity are quite different for those using assistive technologies, especially mobility devices. Although devices that promote movement and activity are beneficial in averting deconditioning and loss of muscle strength, long term use can lead to stresses on joints and overuse in both the upper and lower body [22, 30] and long term pain or discomfort can lead to abandonment.[31] Iezzoni (2003) points out that the efficiency and comfort of wheeled mobility can often outweigh the traditional rehabilitation goals of prostheses and other devices that promote walking. For example, Senator Max Cleland experienced such severe pain and discomfort that he chose to use a wheelchair rather than prostheses for most his life.[32]

The long term use of technology requires attention to the lifespan of devices as well as their users. Assistive technologies must be acquired, maintained, repaired, and eventually replaced or updated.[33] Users may resist changing or updating a technological solution that has worked even in the face of declining function, co-morbidities, dementia, and availability of new technologies.[4] These “assistive technology luddites” evolve from comfort with existing equipment; fear of making changes; or from lack of resources, including appropriate information and assessments to help them update their toolkit. Often the initial acquisition of the device is paid by insurance but repairs and replacement are not always covered.

Internet Use and Disability

The Pew studies of Internet and American life report that, as of 2010, adults with sensory, memory, or ADL/IADL disabilities are significantly less likely than other adults to go online (54 versus 81% overall) and almost 3% of adults surveyed reported that a disability makes it very difficult or impossible for them to use the internet at all.[34]

Some of the inequalities observed in the use of information technology result from disadvantages of living with a disability that limit access to computers, such as lower socioeconomic status. Persons with disabilities are less likely to have internet connections in their home and those who do often have poorer quality access and slower connections. However, net of access and other factors, living with a disability is still strongly associated with lower computer and internet use.[34-35] Interfaces for accessing online information are designed for young mainstream users, and persons with sensory, physical or intellectual disabilities have difficulty with input devices and content displays.[36-37]

For adults with intellectual disabilities, access to computers appears to matter less than family attitudes and knowledge, and training opportunities.[37] Adolescents with disabilities often live with caregivers and other family members who restrict their access to computers, and warn them more often about the dangers of being online, which is consistent with studies that report parents tend to be more protective of children with disabilities.[29] It seems likely that adults with caregivers also would depend upon their knowledge and attitudes. A generational divide in computer skills may affect the online opportunities of aging adults

with disabilities, since the older parental caregivers of middle aged adults are likely to be less comfortable with computers and less sophisticated as users.

Adults with disabilities who live independently or in group settings may be targeted by internet scams and other forms of online predation, especially as they age. Medical equipment scams are among the most common forms of fraud targeted at older persons, and those aging with disabilities may be more vulnerable than others. Some forms of advantage may be more subtle and play on the desire by many individuals with disabilities to improve their circumstances. In Katherine Newman's studies of poverty in America, she found that home care workers who had been permanently injured were sometimes lured into paying high tuition for online courses in the often futile hope of using an internet certification to get a new skilled job.[38]

Mobile computing and portable internet devices embody great promise both as tools for communication and as controllers that can be integrated with other technologies, to make them "smarter." Smart devices are particularly promising in improving independence for those with cognitive disabilities: the mainstream applications of electronic organizers and reminders are ideal to provide cognitive aids to memory and orientation, as well as providing stimulus to help in sequencing actions to complete tasks (customized applications are being developed in rehabilitation to facilitate this). Studies of cognitive aids have however shown that adults with developmental disabilities often require substantial support in order to use devices effectively.[39]

Usability of wireless devices is limited by interface issues such as speech to text conversion and hearing aid compatibility.[40] As new touch screen devices become more widely adopted, the possibilities of global connectivity and equality of access to information are increasingly apparent. Yet, device developers initially invested little attention to accessibility modifications. For example, a flat touchscreen interface is unusable for persons with visual impairment who require tactile feedback[41] and difficult for individuals with tremor or other touch limitations. Recent releases of voice control features and other adaptations begin to redress this and the promise of mobile devices is growing rapidly.

Despite an increasing number of blogs and websites sharing information about disabilities, the potential of social media and interactive online applications ("Web 2.0") for individuals with disabilities is largely unexploited. For example, participation and social support could be improved by the enjoyment of virtual communities and VOIP services.[42-43] As the generations that take advantage of online interactivity age, these tools are becoming more attractive for interventions. In particular, use of online gaming platforms for health education, and home game consoles (such as Wii, Xbox, and Kinect) to deliver specialized fitness, strength training, and rehabilitation in home and hospital settings, as well as the growth in tablet based "apps" to promote wellness and monitor health.[44-46]

Integration of IT and assistive technology: Technology Convergence

The term *convergence* is used to represent the integration of multiple devices or systems into a single platform, in some cases to perform multiple tasks. The increasing use of "intelligent" systems and eventually robotics is a growing area of development in assistive

technologies. The growth in these types of applications has been fueled in part by the popularity of smartphones and tablet computers, which in their design bring together technologies that were once available only on separate platforms. A few years ago, studies of the use of GPS devices to reduce wandering among Dementia patients relied upon specialized systems that were not widely used. Now the integration of GPS into automobiles and smartphones as standard technology has brought this technology into the mainstream.

Devices that are customizable are highly desirable solutions for individuals with varied constellations of functional needs. Dr. Sheila Fitzgerald, a researcher at the Johns Hopkins Bloomberg School of Public Health, for many years adapted to the progressive mobility problems of Multiple Sclerosis with a scooter, and minivan equipped with a lift. In 2011 she started using a neuroprosthesis which employs sensors and electrical muscle stimulation customized to her body to correct the foot drop associated with her MS, and helps her to walk instead of riding. Although it is hard, and slower than using her scooter, she reports that it si meaningful to her to be able to “look colleagues in the eye,” and “stand on your own two feet and navigate the world.”[47]

One of the benefits of developing devices that are designed to run on software is that they can more easily be designed to be modifiable for different applications. Customization is a basic feature of computerized applications and incorporated into most software designs. Programmable hearing aids are one example of this type of “smart” device that is quite common now (though expensive). Other customizable technologies include closed captioning on televisions that are available in multiple languages, or telehealth devices which can be connected to appropriate medical devices, such as blood pressure cuffs to transmit readings directly to providers.[48]

Highly advanced technologies are an important new frontier, but they are not without cost (both financial and otherwise). Since insurance coverage for assistive technologies remains quite limited, the user often bears the burden of buying and maintaining many of their own devices. Smart technologies are often more expensive than other devices, and may require more frequent “upgrades.” A neuroprosthesis like Sheila Fitzgerald’s can cost around $10,000, even without therapy and other ancillary services. Breakdowns in computerized devices likely require highly skilled and specialized repair solutions, and an individual who relies upon such technologies for day to day functioning needs to have access to ongoing support. Maintenance and repair of devices has always been an issue for assistive technology users, but user support is even more important for these complex devices.

There also is real justification for the fear that the increasing complexity of IT driven devices, compared with simpler mechanical technologies, may lead to solutions that are more complex than the problems they address. Simplicity in the user interface is an important part of the design requirements for any devices that make use of these types of computerized controls. Luckily, there has been a revolution in usability driven by mobile internet-devices that place a priority on intuitive, easy to use human-computer interfaces, and many of the mainstream tools being developed to facilitate interaction with these devices improve their usability for persons with physical and intellectual disabilities.

Cohort differences in disability and receptivity to technology

Changes in the prevalence and types of disabilities in future cohorts will certainly occur as medical interventions extend life and improve outcomes for persons with disabilities at all ages. Those who are now young and middle aged will bring many different life experiences to older ages especially with regard to technology. As individuals live longer with disabilities, attention should be paid to increasing differences between cohorts in their need for and ability to use technological solutions to their disabilities.

Persons who are today aging with disabilities were born into eras when the understanding and tolerance of disabilities was very different than it is today. Those who were born with developmental disabilities, or who acquired childhood injuries and conditions, were raised in a time when childhood disabilities were not well understood or accepted. Many were subject to institutionalization and isolation, growing up less educated and with worse job prospects than their peers.[4] Independent lives for many of these individuals were impeded by attitudes that limited their life opportunities, and many came to mid- and later-life dependent upon aging parents and without independent economic resources to care for themselves.

Yet, we are now beginning also to see the aging of cohorts that came of age during and after the rise of social movements around disability and changes in disability policy. The transition from medical to social models of disability that has characterized the development of frameworks like the ICF, for example, shifts the location of disability from the individual to the environment At the same time, large scale social changes in the 1960s and 1970s, from the return of Vietnam veterans to the development of the Independent Living Movement affected the perception and treatment of persons with disabilities, and led to landmark legislation like the Americans with Disabilities Act (1990, reauthorized 2008) which emphasizes the rights of persons with disabilities to full participation in society. [49] While the implementation of the ADA has not always been seamless, the evolution of environmental accessibility and individual acceptability should lead to greater feelings of self-efficacy among younger cohorts and thus greater potential for independent use of technology to compensate for functional limitations.

To the extent that access to education and employment opportunities also are improved, new cohorts aging with disabilities will be better able to afford devices; will be more knowledgeable about their own care; and more receptive to technologies that allow them to function independently. The gatekeeping function of family members and other caregivers may be of less importance as these cohorts age. Younger people with disabilities can be expected to begin using technologies at earlier ages and to be more active consumers of devices, with greater involvement in their own care planning.

Technology also has changed the nature of all types of activities. This transformation is most evident in the nature of work. The skills needed and valued in jobs have changed—in some ways this may be a great benefit to persons living with physical disabilities, since many new jobs have lower physical demands than in the past. However, the growth of jobs in information and service sectors also comes with a higher premium on college education, making the accessibility of education increasingly important to the productive capacity of

persons aging with disabilities. Those with intellectual disabilities, many of whom have both mental and physical impairments, may face more challenges in the changing labor market, and thus have less access to the resources they need as they age. This plays out differently across birth cohorts: the adults with disabilities who are caught in the midst of this shift in labor market opportunities may fare worse in old age than younger cohorts who are in school now. Longer term follow up of the school based studies, such as the National Longitudinal Transitions studies from the 1980s and 2000s, might add evidence to help understand the implications of education for long term opportunities.

Conclusions

Technologies, both high and low, have transformed all of our lives. Assistive technologies are widely used to help those with disabilities function more independently. Persons aging with disabilities will have used devices for many years when they enter the older ages, and bring with them the benefits of a lifetime of using technology. They also will encounter the aging of their devices and the challenges of rethinking their solutions as their needs and the available technologies change. Technological innovation, especially the development and integration of information technology with assistive technologies, has opened a portal to the development of increasingly powerful, individualized tools to assist individuals with disabilities to meet their needs. Yet, issues of access and usability remain to be solved for the usefulness of “smart” technologies to be fully realized.

Persons with physical and intellectual disabilities bring to old age a lifetime of different experiences with both assistive and information technology. There will be a shift from the cohorts who are aging today with disabilities, and who often experienced isolation, poor prospects for employment and limits to adult accomplishments. New cohorts aging with long term disabilities will have come of age during and after social movements that raised the awareness of rights for people with disabilities. These cohorts should survive to older ages with greater ability to use independent technological solutions to adapt as they encounter new challenges and complications from the chronic conditions that develop in later life.

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