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Review Article

The potential for technology to enhance independence for those aging with a disability

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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. © 2014 Elsevier Inc. All rights reserved.

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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] Goals to improve accessibility and equality for persons with disabilities can best and most cost-effectively be achieved by leveraging 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 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

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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 toward 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

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