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*SMART TECHNOLOGY  
FOR AGING,  
DISABILITY, AND  
INDEPENDENCE*

The State of the Science

Editor

**WILLIAM C. MANN**

 **WILEY-  
INTERSCIENCE**

A JOHN WILEY & SONS, INC., PUBLICATION



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*To my wife, Gwen  
And my children, Stephanie and Jennifer  
Who provide love and purpose*

*To my sister  
Lynda  
For her spirit and strength*





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# *PREFACE*

This book focuses on strategies for promoting independence and quality of life for people as they age, with a major focus on emerging technologies. We have drawn from the December 2003 *International Conference on Aging, Disability, and Independence*, the professional literature, and product descriptions to provide an overview of today's assistive technology to support independence. We also report on research and development underway for the next generation of assistive technology and smart environments.

This book is the first in a two-volume set. The second book, edited by Dr. Sumi Helal, will provide a more technical discussion of the topic. Our audience for this first less technical book includes health-care providers, older persons who might benefit from the technology, and caregivers of people with disabilities.

The first chapter of this book provides the groundwork by providing definitions of terms, along with a look at the changing demographics in the United States and throughout the world. Chapters 2 through 4 are grouped as Part I: Smart Technology for Aging, Disability, and Independence. In Part I we discuss smart homes, robotics, telehealth, and other devices and high-technology solutions to promote independence. Chapters 5 through 10 form Part II, which includes some focus on technology, but covers other very critical areas in relation to maintaining independence as we age. These areas include use of basic assistive technology, driving, transportation, community mobility, and home modifications and universal design.

The book is edited by William C. Mann, who directs the Rehabilitation Engineering Research Center on Technology for Successful Aging at the University of Florida (UF). Nine UF Rehabilitation Science Ph.D. students participated in writing this book, each authoring or co-authoring chapters. Bradley R. Milton, the architect who designed the UF Gator-Tech Smart House, contributed to Chapter 2 with an architect's perspective on smart houses, and he faced the challenges of designing a smart house that also serves as a research lab.

Sincere appreciation is expressed to the sponsors and participants of the 2003 International Conference on Aging, Disability, and Independence (<http://icadi.phpf.ufl.edu/2003/>), the consumers who shared their perspective on technology, and those who granted us permission to use their pictures, tables, and figures; we also thank Elena Casson, who provided organizational and editorial assistance with this book.

*William C. Mann*



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# AGING, DISABILITY, AND INDEPENDENCE: TRENDS AND PERSPECTIVES

William C. Mann

## 1.1 INTRODUCTION

---

This book focuses on strategies for promoting independence and quality of life for people as they age, with a major focus on emerging technologies. We have drawn from the December 2003 International Conference on Aging, Disability, and Independence (ICADI), the professional literature, and product descriptions to provide an overview of the state of today's assistive devices to support independence. We also provide a glimpse into research and development of the next generation of assistive devices.

We begin this chapter with definitions of the key terms: technology, aging, disability, and independence. This is followed by a compelling argument for the need to promote independence for people as they age. We discuss population trends that clearly demonstrate the increasing numbers of people who are considered old, along with their independence-related needs. We follow this with a model for viewing disability and independence, and we discuss each of the types of impairment that can be addressed with compensatory strategies such as assistive technology and environmental interventions. We also discuss personal assistance, along with its relationship to assistive technology. In developing technology and modifying the environment, those who know best about what is most appropriate are the intended users: the "consumers." We conclude this chapter with a major section on "consumer perspective."

## 1.2 KEY TERMS: TECHNOLOGY, AGING, DISABILITY, AND INDEPENDENCE

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**Technology** In this book we discuss technology that can support people as they age. The terms *assistive device*, *assistive technology*, and *assistive technology device* are all used interchangeably. The term *assistive technology device* was first

defined in federal legislation in the United States in the Technology-Related Assistance for Individuals with Disabilities Act of 1988 as *any item, piece of equipment, or product system—whether acquired commercially, modified, or customized—that is used to increase, maintain, or improve functional capabilities or individuals with disabilities*.<sup>1</sup>

Some approaches that can support people as they age relate more to fixed aspects of our built environment. In a sense this is a form of technology, but we use the term *environmental interventions* to refer to home modifications, from simple removal of throw rugs to adding a ramp or lift to a home. Environmental interventions also include modifications in yards, driveways, sidewalks, and (in apartment buildings) elevators. In the community, environmental interventions include adaptations in such places as public transportation systems, stores, places of worship, and theaters. To maintain independence, elders require an approach that considers the built environment as well as assistive devices.

**Aging** There are many definitions for “the elderly” or “older persons.” Some are tied to eligibility requirements for programs like Social Security. Some definitions include people as young as age 50 (membership in the American Association of Retired Persons), while others reach up to age 70 (past mandatory retirement age for professors in the United States). Most definitions suggest age 60 or 65 as the entry point for becoming an “older person.” In this book, we cite studies that most often use age 65 as the entry point for becoming an “elder” or “older person.” In much of our own research, also reported in this book, we have used age 60 as the youngest age for inclusion criteria for study participants.

**Disability** Disability has been defined in several laws in the United States. The Social Security Administration defines disability in terms of long-term inability to work. The American with Disabilities Act states that a person with a disability is an individual who has a physical or mental impairment that substantially limits one or more major life activities; has a record of such an impairment; or is regarded as having such an impairment. Note that the terms impairment and disability become interchangeable in this definition. Later in this chapter, we discuss a model for viewing disease, impairment, and disability. In this model, and as we use the term in this book, disability refers to the inability to perform tasks and maintain life roles. An older person with impairments may not be disabled if he or she can find ways to compensate for the impairment, such as the use of technology and environmental interventions. Frailty is another term often used in discussing certain groups of older people, especially the very old. While often used but not clearly defined in the past, more recently, the term has been discussed in the medical literature.<sup>2</sup>

**Independence** Independence is an important concept for what we hope to accomplish in our use of technology and environmental interventions. We define independence as the ability to complete basic daily tasks without personal assistance. Basic daily tasks are often divided into two groups: activities of daily living (ADLs) (eating, grooming, dressing, toileting, walking, and bathing) and instrumental activities of daily living (IADLs) (managing one’s house, managing one’s money, shop-

ping, getting to places outside the home, using a telephone). We add to ADLs and IADLs one more important set of activities for older persons: leisure activities. One's perception of their quality of life is related to their independence in ADLs, IADLs, and leisure.

### 1.3 DEMOGRAPHICS OF AGING AND DISABILITY

Each year there are more older people living in the world, and the percentage of total population represented by older people is increasing. Table 1.1 illustrates the percentage of people over age 65 in the world's 25 oldest countries in the year 2000. Italy ranks first, with 18.1% of its population represented by people over age 65. A similar analysis by continent, breaking down the older population into those over 65, over 75, and over 80 years of age, is presented in Table 1.2. The oldest-old—those over age 80—have the highest rate of dependency in basic everyday tasks.

**TABLE 1.1 Percentage of Population over age 65 in 25 Oldest Countries**

Country	Percent over 65
Italy	18.1
Greece	17.3
Sweden	17.3
Japan	17.0
Spain	16.9
Belgium	16.8
Bulgaria	16.5
Germany	16.2
France	16.0
United Kingdom	15.7
Portugal	15.4
Austria	15.4
Norway	15.2
Switzerland	15.1
Croatia	15.0
Latvia	15.0
Finland	14.9
Denmark	14.9
Serbia	14.8
Hungary	14.6
Estonia	14.5
Slovenia	14.1
Luxembourg	14.0
Ukraine	13.9
Czech Republic	13.9

Source: U.S. Census Bureau, 2000.

**TABLE 1.2 Percent of Population over 65, 75, and 80 years of age in 2000 to 2030**

Region	Year	65 years and over	75 years and over	80 years and over
Europe	2000	15.5	6.6	3.3
	2015	18.7	8.8	5.2
	2030	24.3	11.8	7.1
North America	2000	12.6	6.0	3.3
	2015	14.9	6.4	3.9
	2030	20.3	9.4	5.4
Oceania	2000	10.2	4.4	2.3
	2015	12.4	5.2	3.1
	2030	16.3	7.5	4.4
Asia	2000	6.0	1.9	0.8
	2015	7.8	2.8	1.4
	2030	12.0	4.6	2.2
Latin America / Caribbean	2000	5.5	1.9	0.9
	2015	7.5	2.8	1.5
	2030	11.6	4.6	2.4
Near East / North Africa	2000	4.3	1.4	0.6
	2015	5.3	1.9	0.9
	2030	8.1	2.8	1.3
Sub-Saharan Africa	2000	2.9	0.8	0.3
	2015	3.2	1.0	0.4
	2030	3.7	1.3	0.6

Source: U.S. Census Bureau, 2000a.

Figure 1.1 illustrates that 31.2% of those over age 80, and 49.5% of those over age 85 require assistance with everyday activities.

The Administration on Aging of the United States Department of Health and Human Services published a report based on Census 2000 data.<sup>3</sup> In 2000, approximately one out of eight people in the United States were over age 65, about 12.4% of the population. This was an increase of almost 4 million older Americans in one decade. This represents a 12% increase in older Americans. Over the next 20 years, the rate of increase will escalate to 34%, as the baby boomers enter the ranks of seniors. Looking back to 1900, the percentage of the population represented by older Americans has tripled, while the actual number has increased from 3.1 million to over 35 million—more than a tenfold increase.

It is also important to note that the older population as a group is getting older. People are living longer. In 2000, U.S. life expectancy at age 65 was 84.2 years for females and 81.3 years for males. While the 65- to 74-year-old group increased 8 times over the past 100 years, the 75- to 84-year-old group increased 16 times, and those over age 85 increased 34 times. And for those living to age 100, there were 50,545 in 2000, a 35% increase just in one decade: In 1990 there were 37,306

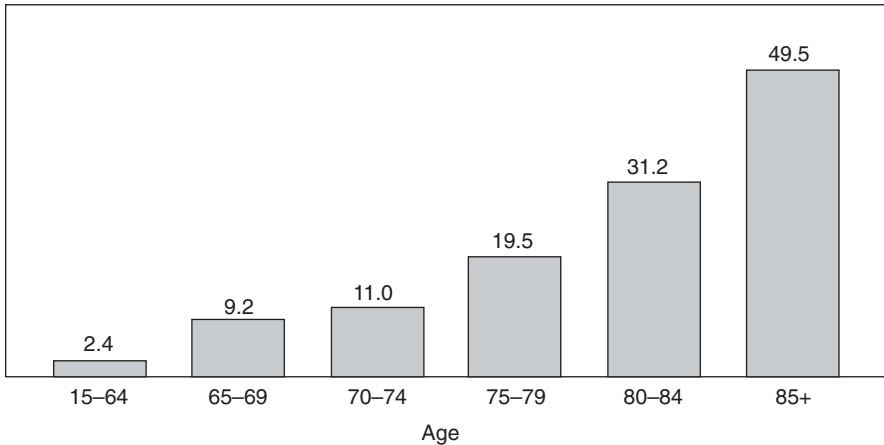


Figure 1.1 Percent of people needing help with everyday activities by age (1991).

Americans over age 100. This trend is projected to continue, with the oldest-old representing the fastest growing segment of our population. This is very relevant for our work in finding ways to promote independence, as it is the oldest-old who have the most difficulty in completing basic daily tasks independently.

The ratio of the number of older women to older men is also increasing. In 2000, there were 1.43 women for every man over age 65. However, for people over age 85, there were 2.45 women for every man. This is directly relevant to the need for finding ways to assist older people in maintaining independence, as women have higher rates of disability than men. With increasing numbers of older people and with more women than men, there will be many more people requiring assistance with basic daily tasks of living.

The number of older people living alone is also increasing. In 2000, approximately 30% of all noninstitutionalized elders lived alone, 40% of older women and 17% of older men. As age advances, the percentage of the age group living alone increases. Half of women over age 75 live alone. Households with more than one person can share the daily tasks of living, and each person in the household can handle those tasks that meet their abilities. When only one person is living in a household, sharing tasks is not possible. This is another compelling reason to develop technologies to assist people in maintaining independence as they age.

The percentage of older Americans living in nursing homes was 4.5% in 2000, representing 1.56 million people. The percentage of the older population living in nursing homes rises sharply with age: from 1.1% of those age 65-74, to 18.2% of those over age 85. Most people prefer to live at home, and the cost of nursing home care is very high. In 2004 in the United States, the cost of a day in a nursing home was on average approximately \$115.00 per day, or \$42,000 per year.<sup>4</sup> Again, this underlines the need to develop approaches to helping older persons maintain independent living in their homes.

Income of older persons is declining in the United States, and this is similar to income trends in most other countries. Overall in 2000, median income was close

to \$20,000 for men and about \$11,000 for women. For men, real median income fell in one year (from 1999) by 2.8%; and for women, it fell by 3.6%. One-third of older persons had incomes under \$10,000 in 2000, and less than 25% reported incomes over \$25,000. Ninety percent of older persons depended on Social Security, while 62% had income from assets, 43% from pensions, and 22% from earnings. Social Security provided 38% of income of older persons. Ten percent (3.4 million) of older persons were below the poverty level in 2000. More women were below the poverty line than men (12.2% versus 7.5%), and those living alone or with nonrelatives were more likely to be below the poverty line (20.8%). An important policy issue relates to how to assist elders in paying for assistive technology.

In the United States there were 21.4 million households headed by older persons in 1999, and 80% of these owned their own home; the remaining 20% rented their home or apartment or lived with others, typically adult children. The age of their homes is important to note, as older homes typically require more repair and are more likely to have been built without thought for the impairments we may face as we age. Half of all homes were built before 1962.

About 4.2 million older Americans (12.8% of the older population) worked in 2000. Of these, 2.4 million were men (17.5% of older men) and 1.8 were women (9.4% of older women). This is a sharp decrease from 1900, when approximately 67% of older men were employed.

As we age, we face age-associated diseases and conditions as well as general decline in function because of the aging process itself. While this book focuses on independence, we recognize that disability is related to disease and trauma. Rather than focusing on specific diseases or trauma, we address applications of technology that can help a person maintain independence even with severe, potentially disabling chronic conditions. In the next section of this chapter we review a model for viewing technology interventions, developed by the National Center on Medical Rehabilitation Research (NCMRR) of the National Institutes on Health (NIH). This is followed by a more detailed discussion of four major impairment categories: movement, vision, hearing, and cognition. We also address fatigue and pain, common symptoms experienced by older persons and which influence independence.

Figure 1.1 illustrates that the older we are, the more likely we are to need help with basic daily tasks: Almost half of those over 85 require assistance with at least one basic activity of daily living. Twenty-six percent of people over age 65 self-reported their health as fair or poor in 1999. Most people over 65 have one or more chronic conditions that can influence ability to engage in activities. The chronic conditions with the highest prevalence include arthritis (49% of older persons have arthritis), hypertension (36%); hearing impairment (30%), heart disease (27%); cataracts (17%), and orthopedic conditions (18%). Older people have more days of hospitalization than younger people (1.6 days on average versus 0.4 days). Older persons also have more contacts with doctors than younger persons, an average of 6.8 contacts in a year versus 3.5 for younger persons. Health costs represent a significant proportion of older persons' out-of-pocket expenditures, an average of 11% (versus an average for the total population of 5%).

## 1.4 A MODEL FOR VIEWING RESEARCH AND DEVELOPMENT IN TECHNOLOGY, AGING, DISABILITY, AND INDEPENDENCE

The NCMRR defines medical rehabilitation as *the study of mechanisms, modalities, and devices that improve, restore, or replace lost, underdeveloped, or deteriorating function*.<sup>5</sup> The NCMRR model includes five terms that help define the level of research and development or of clinical intervention: (1) pathophysiology, (2) impairment, (3) functional limitation, (4) disability, and (5) societal limitations (Figure 1.2). These terms are discussed below.

**Pathophysiology** refers to aberrations in normal physiological processes within our bodies, and research at this level is on cellular structure and events following disease, injury, or genetic abnormality. Most research and development at this level is focused on cure and recovery processes, rather than on compensatory applications and ways of maintaining independence as we age.

**Impairment** relates to the organ (e.g., eyes) or organ system (e.g., cardiovascular) level. We use the categories of hearing, vision, cognitive, and motor and movement impairment throughout this book.

**Functional limitation** is defined as *restriction or lack of ability to perform an action in the manner or within the range consistent with the purpose of an organ or organ system*. We use the term *impairment* more often than *functional limitation*, as we have established our compensatory intervention model based on organ/organ system rather than on specific action.

**Disability** is defined as *a limitation in performing tasks, activities, and roles to levels expected within physical and social contexts*. A person may have difficulty dressing (task), but this could be due to cognitive impairment, vision impairment, or motor impairment, each of which would require a different compensatory strategy. Technology directed at impairment is also likely to reduce disability. If a person uses a hearing aid, it is not simply to improve hearing, but to provide the mechanism for participating in conversations, for attending meetings, and for listening to music.

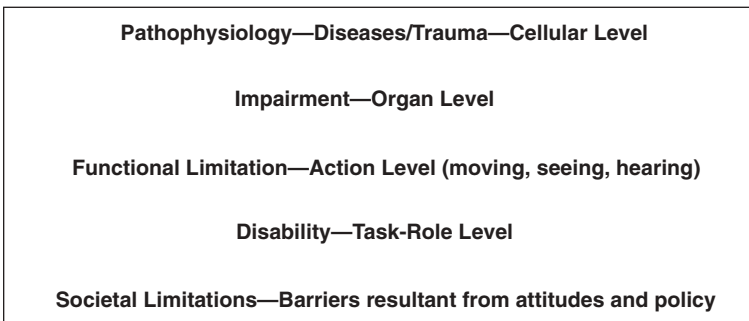


Figure 1.2 Model for viewing research and development and interventions in technology and aging, based on terminology from NCMRR.

*Societal limitations* is the highest level in the NCMRR model, and it refers to barriers resultant from social policy or general societal attitudes. Technology is less often developed to address societal limitations, although it can be employed to do so. All televisions sold in the United States are now required to include a technology that provides closed captioning for people who are hard of hearing or deaf. Alternatively, access to technology applications can be limited by our policy (laws) and attitudes. In the United States, reimbursement under Medicare, Medicaid, and private insurance is very limited for many types of technology that could promote independence, health, and quality of life, while several European countries and Australia have much more liberal policies regarding provision of assistive technologies. Societal attitudes regarding aging also can encourage a more dependent status for older persons.

We have selected the National Institutes of Health NCMRR Model for organizing the approaches toward promoting independence that are addressed in this book. An alternate model is represented by the World Health Organization's *International Classification of Functioning, Disability, and Health* (ICF) (<http://www.who.int/icf/icftemplate.cfm>). The NIH Model is very similar to the earlier World Health Organization's *International Classification of Impairment, Disability and Handicap*. The latest ICF Model has removed many of the more negative terms, and it presents the major concepts with positive terms: (a) functioning versus impairment and (b) social impairment and environment versus handicap. The domains of the ICF are health domains and health-related domains. *These domains are described from the perspective of the body, the individual, and society in two basic lists: (1) Body Functions and Structures and (2) Activities and Participation. As a classification, ICF systematically groups different domains for a person in a given health condition (e.g., what a person with a disease or disorder does do or can do). Functioning is an umbrella term encompassing all body functions, activities, and participation; similarly, disability serves as an umbrella term for impairments, activity limitations, or participation restrictions. ICF also lists environmental factors that interact with all these constructs. In this way, it enables the user to record useful profiles of individuals.*<sup>6</sup> The ICF Model is meant to serve as a unifying language for functional status, health, disability, social impairment, and environment factors.

## 1.5 ADDRESSING IMPAIRMENT (MOTOR AND MOVEMENT, VISION, HEARING, AND COGNITION), PAIN, AND FATIGUE

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### Motor and Movement Impairment

Movement involves the musculoskeletal system and the central and peripheral nervous systems. We move our arms, do fine tasks with our hands, walk, bend, and turn our heads. These movements are used in getting to places and completing tasks. Movement impairment can result from injury or diseases to the musculoskeletal system (e.g., hip fracture, arthritis) and can make it difficult or impossible to use our



hands, walk, or move our trunk and neck. Table 1.3 highlights the prevalence of specific types of movement difficulties. Clearly, as we get very old (over 85 in Table 1.3), a much larger proportion of people have difficulty with basic movements and everyday tasks.

**Arrangement** There are many assistive devices that can compensate for movement impairment, most largely mechanical in form such as canes, walkers, and wheelchairs. More recently there have been advances in wheelchairs, with several teams developing what are called “smart wheelchairs,” designed to prevent collisions: One follows a track laid along the floor, while another uses infrared sensors to detect obstacles at different distances. We discuss these in some detail in Chapter 4.

**TABLE 1.3 Functional Limitations of Persons 65 Years and Over by Age and Type of Living**

Functional Limitation	Persons				Living alone	Living with others
	65 years and over	65 to 74 years	75 to 84 years	85 years and over		
Total 65 years and over:	30,748	18,397	9,920	2,430	9,634	21,214
Percent with difficulty <sup>a</sup>						
Walking	14.3	9.2	18.8	34.9	18.1	12.6
Getting outside	15.9	8.7	22.3	44.8	20.7	13.8
Bathing or showering	9.4	5.6	11.3	30.6	11.2	8.7
Transferring <sup>b</sup>	9.0	5.9	11.6	21.9	10.8	8.2
Dressing	3.9	3.8	7.0	16.1	6.3	5.6
Using toilet	2.6	2.0	5.7	14.2	4.8	3.9
Eating	2.1	1.3	3.1	4.1	2.2	2.0
Preparing meals	8.6	4.5	11.7	27.6	9.1	8.4
Managing money	7.1	2.8	10.3	26.2	8.4	6.5
Using the telephone	7.1	3.8	9.7	21.4	7.1	7.1
Doing light housework	11.4	6.6	15.5	30.8	13.6	10.4
Percent of total receiving help <sup>c</sup>						
Walking	5.9	3.3	8.2	16.8	4.9	6.4
Getting outside	13.2	6.3	18.8	42.3	17.2	11.4
Bathing or showering	5.9	3.3	7.0	20.9	5.0	6.3
Transferring <sup>b</sup>	3.9	2.5	4.8	11.0	2.7	4.5
Dressing	3.9	2.3	5.0	11.1	2.7	4.4
Using toilet	2.6	1.3	3.9	7.8	1.9	2.9
Eating	1.1	0.5	1.9	2.5	0.8	1.2
Preparing meals	7.5	3.6	10.5	25.4	7.0	7.8
Managing money	6.4	2.5	9.1	24.6	7.4	5.9
Doing light housework	8.9	4.8	12.1	27.3	9.6	8.7

<sup>a</sup> Difficulty due to a physical or mental health condition.

<sup>b</sup> Getting in or out of a bed or chair.

<sup>c</sup> Receiving help due to a physical or mental health condition with the specified difficulty.

Source: U.S. Bureau of the Census. 1991 Survey of Income and Program Participation. Functional Limitations and Disability File, wave 3, unpublished tabulations.

At the “societal limitations level,” mobility has been enhanced through curb cuts where streets meet sidewalks, as well as through ramps and lifts on the outside and inside of public buildings. In the United States, legislation such as the Architectural Barriers Act (1968) and the Americans with Disabilities Act (1990) ensure that people with disabilities have access to public buildings.

Research and development in the area of technology, aging, and independence for people with motor and movement impairment will address better ways to move about, as well as assistance with tasks that require our arms and hands. More development of helpful, personal robotic devices is needed—robotic devices that can complete tasks, fetch objects, and assist in walking (sensing fatigue and unsteadiness and providing more support or the opportunity to sit and rest).

## Vision Impairment

Most elders with vision impairment are not totally blind, but rather have partial or low vision. Today eye disease is being diagnosed and treated much earlier than in the past, and this has led to a greater proportion of older persons with low vision. Approximately 8.6% of Americans over age 18 experience problems with vision, even with corrective measures. Older persons have a much higher incidence. By 2020, there will be approximately 54 million blind persons over age 60 worldwide. The severity of vision loss and the resulting limitations vary with age of onset, support systems available, and coping strategies.

There are a number of low-technology products to assist people with vision impairment, eyeglasses being the most common. Other devices include magnifiers, larger-size products (such as large clocks, thermostats, television remote controls, and game boards), and alerting devices such as the EZ Fill, which makes it possible for a visually impaired person to add hot or cold liquid to a container—a buzzer sounds to alert the user when the liquid is poured to 1-inch from the top. There are a number of talking products—such as talking thermometers, watches, and clocks. These products are discussed in more detail in Chapter 9.

There also are a number of more high-tech assistive products for people with vision impairment. These include video magnifiers, such as (1) the pocket-sized Pico <http://www.telesensory.com/products2-1-16.html>, which offers full color and negative modes with magnification up to 5×, and (2) the somewhat larger but still portable MiniViewer, which provides (a) magnification from 5× to 15× in both color and black-on-white or (b) inverse white-on-black, which is easier for some people with vision impairment to read. Desk-sized electronic magnifiers include such products as the Aladan Pro 75 and the Smartview 1000. There is a significant level of research and development in high-technology devices for people with low vision and people who are blind. We cover this in Chapter 4.

At the “societal limitations” level in the NCMRR model, we have seen legislation in the United States that requires that audible traffic signals, where appropriate, be included in new transportation plans and projects [Sec. 1202(g)(2)].<sup>7</sup> Accessible pedestrian signals (APS) provide audible and/or vibrotactile information coinciding with visual pedestrian signals to inform blind pedestrians when the WALK interval begins.

**Hearing Impairment** In the United States, 33% of people over age 65 have hearing impairment, and this will increase, because there are more people age 45 to 64 with hearing loss than those 65 and older. Loss of hearing is so gradual that many older persons accept the loss as a normal process of aging and do not seek assistance. Hearing loss impacts negatively on communication and can result in isolation and depression. Hearing loss can also impact on safety and health in other ways as well, such as failing to hear a fire alarm or not being able to clearly understand a pharmacist's directions for taking medications.

Low-tech assistive devices for hearing loss include vibrating alarm clocks and smoke detectors, flashing-light doorbells, and a variety of sound amplification products. Some of the sound amplification products could be considered high tech, such as advanced assistive listening devices, which like hearing aids can be digitally adjusted for individual users. In the high-tech realm, development of smart phones with voice-to-text translation could provide a universal communication tool for people who are hard of hearing or deaf. Low-tech hearing devices are discussed in more detail in Chapter 9, and high-tech devices are covered in Chapter 10.

**Cognitive Impairment** Approximately 10% of people over age 65 have cognitive impairments that impact on their ability to complete everyday tasks independently. Alzheimer's disease results in a progressive decline in cognitive performance, and it is the most common cause of significant cognitive impairment in people over 65. Stroke is the second most frequently occurring cause of cognitive impairment. With impaired cognitive function, a person may experience confusion, disorientation, limited attention, memory impairment, and decreased ability for learning. A person's activities of daily living are influenced by impaired cognition. A person with Alzheimer's disease will decline in ability to meet safety, self-care, household, leisure, social interaction, and vocational needs. Eventually, the person will lose the ability to perform basic activities of daily living, including eating, dressing, toileting, grooming, bathing, and locomotion.

An emerging area of research is focused on assisting persons with cognitive impairment in their daily activities through the use of computerized devices. In some cases, devices being developed are in the form of a prompting system to guide elders with cognitive impairment through basic daily tasks. Related studies suggest that even individuals with severe cognitive impairment might benefit from a prompting device/system. As a group, people with cognitive impairment have traditionally used the fewest number of assistive devices—even if they had other types of impairments. We must develop smart devices and smart systems that make it easier for a person with a cognitive impairment to participate in even the most basic daily tasks. Development of robotic assistants for people with cognitive impairment should also be a goal. We address these devices and systems in the following chapters.

**Pain** Pain is a very common experience of older adults: Close to 85% of elders have conditions such as arthritis, peripheral vascular disease, and degenerative neurological conditions that can cause pain.<sup>8</sup> The percentage of elders who actually experience pain has been estimated to be in a range between 2% and 40% of the

population.<sup>9</sup> Location of pain varies, but one study found that headaches are most common, impacting 78% of all people in the United States within one year; backache ranks second, with 56% of people impacted, followed by muscle pain 53%, joint pain 51%, and stomach pain 46%.<sup>10</sup> The percentage of people experiencing pain increases with age. Trauma from accidents, especially those that result in fractures, is another major cause of pain.<sup>11</sup> Pain is most commonly diagnosed through self-report.<sup>12</sup>

Approximately 18% of older people in the United States take medication for pain, with more than half taking it for over 6 months.<sup>13</sup> Typically, a medication intervention is begun with acetaminophen; if this does not work, nonsteroidal anti-inflammatory drugs are prescribed. Pain, especially joint pain, appears also to be a contributor to disability.<sup>14</sup> Pain also appears to be associated with late-life depression,<sup>15</sup> which in turn can impact functional status. Pain may be difficult to diagnose for a person with cognitive impairment, if they are not able to communicate their experience with pain. In these cases, one must rely on facial expressions, alterations of movement, and reports by others who are close to the elder. Development of technology to detect pain in nonverbal cognitively impaired elders would be a major advance.

**Fatigue** Fatigue can impact independence, making it difficult or impossible to get to places beyond the home, to participate in favored leisure activities, and to complete ADLs. Fatigue is a common symptom of many diseases. For people with cancer, fatigue can be a major activity-limiting factor. A recent study demonstrated an association between fatigue and pain, mood, and sleep, with pain being the most highly associated. In this study, pain accounted for the largest amount of variance in fatigue, but mood modified this relationship. The authors stressed the importance of assessing pain when someone reports fatigue.<sup>16</sup>

## 1.6 PERSONAL ASSISTANCE

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In varying degrees, we all rely on others for many things. However, when it becomes difficult or impossible for us to independently complete ADLs and/or IADLs, either a technology intervention is needed or personal assistance is required—often it is a combination of both. Our basic assumption is that it is best to maximize independence through technology and environmental interventions, recognizing that some degree of personal assistance may also be required. As a person’s abilities decline, then both the technology and the amount of personal assistance must be adjusted.

Many older persons rely on their spouse for personal assistance. Often they may both have impairments, but have complementary abilities that allow them to be “independent couples.” Others rely on adult children, other family, friends, and neighbors. We refer to these groups as “informal caregivers.” When assistance from informal caregivers is insufficient, formal, paid caregivers are needed.

When a spouse or adult child provides caregiving for an older person, they may themselves be older and facing impairments. Assistive devices and home modifications that promote independence can assist both the elder with a disability and

the caregiver. Assistive devices, such as lifts, may be essential for tasks that require strength or endurance beyond the capability of the caregiver.

## 1.7 CONSUMER PERSPECTIVE

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### Consumer Perceptive: The AARP Report

The ICADI Consumer Perspective Track featured a keynote presentation by Dr. John C. Rother of the American Association of Retired Persons (AARP). Dr. Rother summarized the AARP recently published report, *Beyond 50: A Report to the Nation on Independent Living and Disability*, which drew heavily on the views of older persons themselves. Key findings from this study are presented in this section. The report provides new analyses of the federally sponsored Medical Expenditure Panel Survey and the National Long-Term Care Surveys and an AARP survey conducted by Harris Interactive. This section is drawn from the Executive Summary of this AARP report.<sup>17</sup>

***(1) Persons 50 and older with disabilities, particularly those age 50–64, strongly prefer independent living in their own homes to other alternatives. They also want more direct control over what long-term supportive services they receive and when they receive them.***

*Loss of independence and loss of mobility are what people with disabilities 50 and older say they fear the most as they look to the future. They also say having more control over decisions about the services and help they receive would cause a major improvement in their current lives. For example, a large majority of people with disabilities would prefer to manage any publicly funded in-home services themselves, rather than have an agency do so. In addition, a majority would prefer cash payments for such home care services over services provided directly by agencies.*

***(2) Many persons with disabilities, especially those with severe disabilities, have unmet needs for long-term supportive services and assistive equipment in their homes and communities. Some of these needs would be relatively simple to meet; others, such as providing more personal assistance services, would require significant resources and our collective will.***

*Only about half of persons 50 and older with disabilities report receiving any regular help with daily activities from one or more people. The vast majority of such help is the unpaid assistance of family or other informal caregivers. In addition, only one out of three uses any community-based service. Because there is no organized “system” for delivering services, many individuals do not know about sources of support or how to find them, or if they are eligible for any publicly funded services.*

*Our data indicate there are high levels of unmet need among persons 50 and older with disabilities:*

- *Almost one-quarter report needing more help than they receive now with basic daily activities, such as bathing, cooking, or shopping.*
- *One-half said they were not able to do something they needed or wanted to do in the past month because of their disability. These needs were very basic, such as doing household chores, getting some exercise, or getting out of the house.*

- *More than one-third of homeowners would like to make home modifications that would make their lives easier, such as installing grab bars in the bathroom, but have not done so, largely because of cost.*

**(3) *On average, people with disabilities 50 and older give their community a grade of B-/C+ as a place to live for people with disabilities. While some community features receive good marks, others are rated poorly by persons with disabilities, particularly public transportation. In addition, many older residents of federally subsidized housing are at risk of needing more supportive housing environments with services.***

*Barely one-third of respondents currently give their communities a “B” or higher rating for having dependable and accessible public transportation. Getting safely to places they want to go is the second most important concern persons with disabilities have about their communities. Among persons 65 and older with disabilities, the perception that crime is a serious problem in their neighborhoods nearly doubled, from 4.5 percent to 8.2 percent between 1984 and 1999.*

*Residents in federally subsidized housing for older persons share many of the characteristics of those at high risk of needing long-term supportive services. Subsidized housing residents are overwhelmingly female, report more disabilities than older persons who do not live in subsidized housing, and are less likely to have someone to whom they can turn if they become sick or disabled.*

**(4) *Family support remains strong, but the impact of such trends as greater longevity, more women in the labor force, and greater geographic dispersion is now hitting home. Either in person or “at a distance,” families are finding themselves with new roles as caregivers to aging parents, spouses or siblings, aging children with developmental disabilities, and other relatives and friends. Caregivers age 50 and older often experience considerable stress as a result of their caregiving roles.***

*Strong social support from families and friends can protect against functional decline and help individuals cope with functional decline if it occurs. While contact between persons 65 and older with disabilities and their families and friends remains strong, it has declined since the mid-1980s.*

*Larger social trends are affecting the composition of families and their roles as caregivers, including the growing number of women in the workforce who must juggle work and caregiving responsibilities. Among 50- to 64-year-old caregivers, 60 percent are working full- or part-time. In addition, significant economic sacrifices during peak earning years are common among caregivers 50 and older who have been in the workforce.*

*Parents caring for aging children with cognitive and developmental disabilities represent a growing group in the older caregiver population. This trend reflects the emergence of two-generation families in which parents among the older or oldest age groups are caring for children who are in their 50s and 60s.*

*A preference for family assistance for help with everyday tasks is even stronger among persons 50 and older with disabilities than among persons 50 and older in the general population. This preference declines somewhat when 24-hour care is needed.*

**(5) *Inadequate health insurance is at the top of the list of problems experienced by persons with disabilities 50 and older, including those with Medicare coverage. In addition to gaps in coverage, such as the lack of coverage for prescription drugs, problems range from inappropriate care for chronic conditions to lack of coordination between medical care and long-term supportive services for persons with disabilities.***