

AGING, DISABILITY, AND INDEPENDENCE: TRENDS AND PERSPECTIVES

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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

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*.¹

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.²

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.³ 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

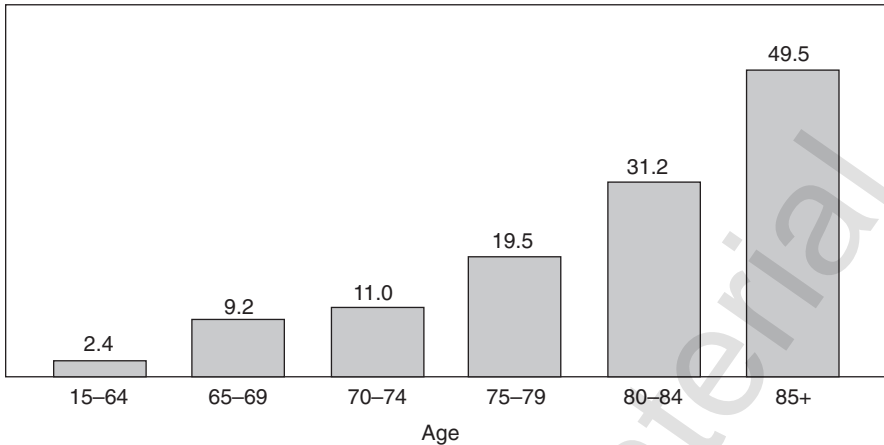


Figure 1.1 Percent of people needing help with everyday activities by age (1991).

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.⁴ 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*.⁵ 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.

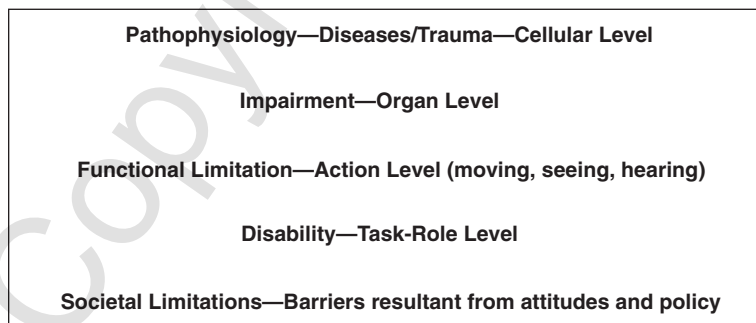


Figure 1.2 Model for viewing research and development and interventions in technology and aging, based on terminology from NCMRR.

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.*⁶ 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

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 65 years and over	65 to 74 years	75 to 84 years	85 years and over	Living alone	Living with others
Total 65 years and over:	30,748	18,397	9,920	2,430	9,634	21,214
Percent with difficulty ^a						
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 ^b	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 ^c						
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 ^b	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

^a Difficulty due to a physical or mental health condition.

^b Getting in or out of a bed or chair.

^c 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)].⁷ 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.⁸ The percentage of elders who actually experience pain has been estimated to be in a range between 2% and 40% of the

population.⁹ 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%.¹⁰ The percentage of people experiencing pain increases with age. Trauma from accidents, especially those that result in fractures, is another major cause of pain.¹¹ Pain is most commonly diagnosed through self-report.¹²

Approximately 18% of older people in the United States take medication for pain, with more than half taking it for over 6 months.¹³ 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.¹⁴ Pain also appears to be associated with late-life depression,¹⁵ 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.¹⁶

1.6 PERSONAL ASSISTANCE

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

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.¹⁷

(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.*

People with disabilities say better medical insurance is the number one change that would be a major improvement in their lives. In addition, one out of three persons with disabilities reports specific needs, such as for particular therapies or equipment, not covered by health insurance. Problems include delivery as well as coverage issues: The overlap between chronic conditions and disabilities increases with advancing age, but little coordination exists between medical care and long-term supportive services. Finally, the trends concerning access to and satisfaction with health care among people 50 and older with disabilities over the last four years are in a negative direction. Concerns about recent trends extend to programs that have historically played a positive role in the health care of people with disabilities. Persons 50–64 with disabilities rely much more heavily on Medicaid than do those without disabilities, but Medicaid budgets are being cut in many states due to budget crises.

(6) Despite some improvements, the quality of long-term supportive services is a persistent problem in all settings. A focus on consumers' quality of life is rare. In addition, there is an unprecedented shortage of the frontline workers needed to provide long-term supportive services to persons with disabilities, such as personal care attendants and nursing assistants.

While the quality of care in nursing homes has generally improved with the passage of the Nursing Home Reform Act in 1987, problems with quality of care and quality of life persist. Two-thirds of persons 50 and older with firsthand experience with nursing homes believe the government is not doing enough to enforce quality standards. Low staffing levels lead to poor care in nursing homes. According to a recent report sponsored by the Centers for Medicare and Medicaid Services, 91 percent of nursing homes do not provide the minimum number of hours of care by certified nurse assistants needed per resident per day to avoid serious quality-of-care problems.

Difficulty in recruiting and retaining direct service staff, such as nursing assistants and personal care attendants, is growing. According to some estimates, the need for these workers will double over the next decade. Unmet need for registered nurses is also increasing. Reports of quality problems also continue in assisted living facilities, despite efforts to support residents' privacy, choice, and independence. Efforts to promote quality in supportive housing other than assisted living have been sporadic at best.

(7) The costs of long-term supportive services, which individuals typically need at the time their income is most limited, are often unaffordable to individuals with disabilities and their families.

The need for long-term supportive services can be financially catastrophic to individuals with disabilities and their families, even those with substantial income and resources. A recent study estimated that only 27 percent of older persons have sufficient income and assets to be able to withstand a long-term care "shock" totaling \$150,000 over three years without impoverishing themselves. Lower- and middle-income Americans with disabilities often find that their options are limited and out-of-pocket costs are burdensome. In the AARP/Harris Interactive survey, persons 50 and older with disabilities with incomes "in the middle" were the income group most likely to say that having a way to pay for long-term supportive services (such as help with bathing or shopping) and equipment would be a major improvement in their lives.

The high costs of a long-term disability remain largely uninsured. Public programs such as Medicaid pay only after individuals have spent down their income and exhausted their assets. Private health and long-term care insurance account for only 11 percent of total long-term care expenditures in the United States. Disability income insurance policies aimed at replacing lost wages usually end by age 65 or earlier.

Long-term care is the single largest component of direct health-related out-of-pocket spending by Medicare beneficiaries, followed by spending on prescription drugs. Moreover, the indirect costs of providing long-term supportive services in the home, borne by unpaid family members and friends of persons with disabilities, are immeasurable.

Consumer Perspectives on Assistive Technology: Low-Technology Devices

The most important factor in providing assistive technology and home modifications for elders is the perspective of the person who will receive these interventions. Elders need to be informed fully about their disability in order to participate in the selection of the most appropriate devices. Service providers need to consider the priorities of elders: What do they want to be doing, and do they really want or feel the need for recommended devices? Have they been fully informed about options for different types of devices? Older people represent a very heterogeneous population, and their use of assistive technology varies in large part based on their perception of need, their interests, the impairments they face, their health, and their social supports.

The National Institute on Disability and Rehabilitation Research (NIDRR) has supported a Rehabilitation Engineering Research Center (RERC) focused on Aging and Disability since 1991. A 10-year (1991–2001) longitudinal study of the RERC-Aging, called the Consumer Assessments Study, has provided an analysis of the use of, and need for, assistive devices and environmental interventions by older persons with disabilities. This study followed a sample of 1103 elders, using interviews and observations in their homes and neighborhoods in western New York and northern Florida. Information gathered included:

- *Basic demographic information* such as age, education, and housing
- *Health status* including number and types of diseases present, use of medications, and use of hospitals and physicians
- *Functional status* including ability to complete activities of daily living (such as bathing) and instrumental activities of daily living (such as shopping for groceries)
- *Psychosocial dimensions* including mental status, depression, self-esteem, and sense of responsibility
- *Social resources* assistance available and caregiver needs
- *Current use of assistive devices* including satisfaction and problems with devices, as well as and ideas for new devices

This section draws on the published reports from the Consumer Assessments study, combining a focus on both assistive technology and environmental interventions.

One of the questions asked by the RERC-Aging Consumer Assessments Study related to activities they could no longer do but they would like to be doing. This question sought to determine if “missed” activities might be possible with an appro-

TABLE 1.4 Activities Most Missed by Elders with Disabilities

Activities	Percent of respondents missing the activity
Doing, watching sports	22%
Driving	18%
Walking	17%
Gardening/housework	15%
Socializing	15%
Traveling	7%
Shopping	6%
Art: Painting, sculpting	6%

appropriate assistive device.¹⁸ Table 1.4 categorizes and ranks the consumer responses to this question. The most missed activities are primarily leisure activities. These activities reflect one aspect of the “consumer perspective”—what is important to the person who might use an assistive device. There are a large number of assistive devices to assist elders with many of the leisure activities they miss. More are being developed.

A major component of the Consumer Assessments Study (CAS) was to explore the consumer perspective on current use of their assistive devices, including their level of satisfaction and problems they were having with their devices.¹⁹ The CAS found that older people owned a mean of 13 devices. They reported using a very high number (mean of 12) and high percentage (mean of 91%) of the devices they own. Overall, satisfaction with devices used was high at 89%. However, while overall satisfaction was high, satisfaction rate varied significantly among different device types. People with arthritis are satisfied with 89% of the devices they own,²⁰ people with hearing impairments are satisfied with 70% of the devices they own,²¹ and people with cognitive impairments are satisfied with 67% of the devices they own.²²

The CAS also explored problems elders reported with their assistive devices. Table 1.5 is a simple ranking of devices by number of problems reported, which suggests that there is a lower degree of satisfaction and more problems with canes as a device type than with any other assistive device. However, with the exception of eyeglasses, there are more canes than any other type of assistive device. Table 1.6 is also a ranking of devices, but is based on a ratio of number of device problems to total number of devices reported in use. In Table 1.6, canes drop from the number one rank, while hearing aids move up to be ranked as the most problematic assistive device relative to number of users.

We will explore consumer perspectives for a few of these devices:

Incontinence Products The incidence of incontinence within the CAS participants is high and reflects the importance of this problem for the population of older people with disabilities. Of our sample of 1103 frail elders, 471 (42.7%) had some degree of incontinence (FIM score of 6 or less on the Sphincter Control/Bladder Management item). This is similar to findings from a 6-year study of 2025 women

TABLE 1.5 Rank Order of Specific Device Categories by Percentage of Devices in Category "Not Used" (N = 1056 Subjects)

Device category	Number of devices owned	Number (n) and percent (%) of devices owned that are not used
Canes	916	297 (32.4%)
Walkers	588	180 (30.6%)
Commode chairs	229	62 (27.1%)
Magnifiers	415	110 (26.5%)
Bath bench/chair/stool	478	103 (21.5%)
Grab bars/rails	961	149 (15.5%)
Wheelchairs	386	50 (12.9%)
Hand-held showers	388	47 (12.1%)
Eyeglasses	802	49 (6.1%)
TV/VCR remote control	882	44 (5.0%)

TABLE 1.6 Rank Order of Specific Device Categories by Percentage of Devices in Category "Not Satisfied" (N = 1053 Subjects)

Device category	Number of devices owned	Number (n) and percent (%) of devices owned that are unsatisfactory
Hearing aids	170	80 (47.1%)
Magnifiers	426	155 (36.4%)
Wheelchairs	373	112 (30.0%)
Canes	899	258 (28.7%)
Walkers	570	135 (23.7%)
Eyeglasses	804	153 (19.0%)
Phones	728	88 (12.1%)
Grab bars/rails	932	99 (10.6%)
TV/VCR remote control	899	94 (10.5%)
Bath bench/chair/stool	536	82 (6.7%)

over age 65 residing in rural Iowa: A 36.3% rate of urge incontinence and 40.3% rate of stress incontinence was found at baseline.²³ Increased age is associated with increased urge incontinence. There are a number of related incontinence products used by Consumer Assessments Study participants: Some were designed specifically for incontinence, such as Depends®, while others were designed for other purposes, such as paper towels and sanitary napkins. Incontinence affects more women than men. For the 471 participants with incontinence, 72.5% were female and 27.5% male. Many of the CAS consumer comments relate to insufficient absorbency of the product, high cost of the product, and poor comfort and fit. Several comments were made by consumers about the inadequate quality of the incontinence products

covered by Medicaid. Comments from many study participants suggest that if certain more expensive incontinence products were covered by Medicaid, or if they could afford them, they would not have a continuing problem with incontinence. Given the association between incontinence and nursing home placement, along with the high cost of nursing home care, it would seem logical for Medicaid and other third-party payers to cover the more satisfactory incontinence products.

Mobility Devices Consumer concerns with mobility devices—canes, walkers, and wheelchairs—resulted in their ranking high in both numbers of problems reported and in the dissatisfaction rate per number of users. Almost half of all problems encountered with canes related to difficult or risky use resulting in incidents of tripping and getting tangled up, or abandonment because the cane was too heavy or clumsy to use. Several consumers' comments related to discomfort: "After long period of use, causes pain in right thumb," "handle hurts hand," and "grip is uncomfortable." Other comments were related to stigma, such as "embarrassed to use."

As with canes, many consumer comments regarding walkers were categorized as "difficult and/or dangerous to use," pointing to the need for careful professional assessment, prescription, and follow-up. A relatively small percentage (4%) of walker owners cited stigma as a problem. In the present study, consumers raised another problem common to many assistive devices: difficulty in transporting the device in the car. Many elders use several assistive devices, yet experience difficulty in transporting them outside the home: getting them down steps, getting them into and out of the car, and using them on surfaces different from those found in the home.

Almost one-third of the Consumer Assessment Study participants used a wheelchair, and 40% of these wheelchair users reported at least one problem with their wheelchair. Problems were grouped into the following categories: "maintenance and repair, such as broken wheels, flat tires, (33% of problems); "fit between user and the chair," such as uncomfortable to sit in, unable to propel self (41%); and "physical characteristics," such as too heavy or too wide (26%). There was a significantly higher percentage of elders with wheelchair problems among those who selected their own wheelchair than among elders whose chair selection involved a health professional.

Two primary reasons for not resolving the wheelchair problems in a timely manner related to the consumer's limited financial resources and their need for more information on maintaining and repairing wheelchairs.²⁴

Bathing Products Consumers reported their reasons for dissatisfaction with bathing devices as related to amount of space required for the device in the bathroom, difficulty in washing while using the device, and preference to sit in their bathtub (down in the water), rather than on a bath chair or bath bench.

Washing Devices Consumers provided many negative comments about washing devices, such as long-handled bath brushes and sponges. These comments included (a) difficulty in handling the device (especially in getting to difficult-to-reach parts of the body) and (b) the device's lack of effectiveness in washing thoroughly. Unlike

incontinence products, expense was not stated as a problem for washing devices. Perhaps this is a reflection of the difference between (a) a product that is disposable and whose supply must be continuously replenished and (b) washing devices that are either infrequently or never replaced.

Controls on Electronic Devices Many consumers reported that controls on electronic devices presented a problem for them. While not all hospital beds are powered, those that are have a hand-held control. One study participant had a problem with the control falling on the floor, so she had it taped on the back of the bed. Another consumer reported difficulty with manipulating the controls. With hearing aids, two consumers simply stated the controls were difficult to adjust; another, who had diminished tactile sensation and vision impairment, reported difficulty not only with the controls, but with inserting batteries; yet another consumer had difficulty putting the hearing aid in the ear due to amputation of fingers. Television remote controls and phones are other common devices that can be assistive, yet often have controls that present problems for a number of older persons with disabilities.

Summary of Reasons for Problems with Devices

In a published article from the Consumer Assessments Study, we listed 14 categories, not all mutually exclusive, into which consumer comments regarding dissatisfaction with devices could be grouped.²⁵ We reproduce this list below with permission of the publisher, IOS Press:

1. *Device does not sufficiently help the person do the intended task(s).* This is a common problem with many of the assistive devices used by older persons with disabilities. In some cases, the device worked well in the past, but the person's condition changed, and the device is no longer adequate. In other cases the device never worked well, often due to the person not having had the opportunity to try the device before securing it, or having secured it without professional guidance. In many cases there are more appropriate devices for the person, but they continue to use the one they have. Examples include incontinence products that lack sufficient absorbency, hearing aids that do not adequately assist the person to hear, canes that do not provide sufficient support, and eyeglasses and magnifiers that lack sufficient power or lighting.
2. *Device does not work equally well in all intended environments or situations.* This is particularly true with mobility devices. Different surfaces render some devices ineffective. For example, it is difficult to self-propel a wheelchair over carpeting for a person who is physically weak and fatigues easily, yet the wheelchair may work well over wooden or tiled floors. Individuals who use carts for shopping have reported that the "street is too bumpy, and the cart will not easily go up stairs." Similarly, reachers may not work well with larger or heavier objects such as cans stored in food cabinets, but work well with magazines or pieces of clothing.

3. *Device calls unwanted attention to the person.* Assistive devices that are most clearly associated with impairment carry the most stigma. Metal frame walkers, mobility canes, and raised toilet seats are examples of devices that are sometimes cited as calling attention to one's impairment. In some cases, the person is embarrassed by having the device in their home, not wanting friends and relatives to see the device. In other cases they do not want to be seen as disabled, for fear they will be an easy target for crime. Many inner-city elders live in neighborhoods that have changed over the years, with crime a significant problem. One man who used a white cane for mobility specifically stated that he did not use his cane in his own neighborhood for this reason.
4. *Device is not affordable.* While some elders know of better device solutions for their needs than the one they use, often they cannot afford the better device. Each age cohort of elders with increasing age is increasingly poorer. Mean income for the oldest-old (over age 85) is below poverty level. Even a relatively inexpensive device, such as a \$30 reacher, may literally be outside the reach of many elders, who barely have sufficient funds for food and shelter. For more expensive devices, such as wheelchairs, print enlargement systems, and computers, only a very small percentage of elders can afford the purchase with their own funds. Medicare and Medicaid have typically covered only durable medical equipment, and the vocational agencies target most of their funds to younger persons with employment goals.
5. *Device could be dangerous in some situations.* Mobility devices are often involved in falls, although there has been little study of the nature of involvement. For a person using a cane or walker, surfaces such as packed snow or ice can be very dangerous. Use of walkers in cluttered environments could lead to tripping and falls. Attempts to grasp heavy items from a cabinet with a reacher that cannot handle the load could result in the object falling on the person.
6. *Device causes physical discomfort.* Devices that require gripping, such as canes and certain types of can openers, can be painful for a person with arthritic hands. Incontinence briefs are uncomfortable for some elders, reporting bulkiness and a "bunching up" effect. Bath brushes with hard bristles can irritate sensitive skin. Hospital beds do not have the same "feel" as a regular bed, and several users of hospital beds describe them as uncomfortable. One elder reported that a backrest support cushion required more padding, as the metal frame on the lower sides was uncomfortable. Several elders reported problems with comfort for their lift chairs: Three stated simply that the chair was uncomfortable; another elaborated, stating the "vinyl makes a lot of noise as the chair moves and you stick to the chair."
7. *Device is not well-maintained.* This is a common problem with devices that have parts that wear out, such as the tips of canes or the pads on the legs of bath seats. It is also common with devices such as cordless phones that require replacement of rechargeable batteries. Even simple, inexpensive devices like bath brushes become worn, but may not be replaced.

8. *Device is not easily transported beyond the home.* Transporting devices in cars and public transportation is often very difficult. Getting wheelchairs in and out of cars may be impossible for the elder and difficult for caregivers. For someone still driving and using a mobility device, having easy access to the device may be essential. The RERC-Aging Consumer Advisory Board reported the difficulties they have in traveling with their assistive devices when they stay overnight in hotels. This led to the publication of the *Hotel-Motel Resource Guide to Assistive Device Loan Closets*, targeted at the lodging industry in the United States available from the University of Florida Rehabilitation Engineering Research Center on Technology and Aging.
9. *Device requires more space than is available.* This is a common problem with bath chairs and bath benches. Many bathrooms are small and are used by several family members, most of whom do not use the device. Bath benches that extend beyond the tub can impede movement in the bathroom. Walkers and wheelchairs may not be used inside the home because of difficulty in moving around furniture. Lift chairs are also a problem for elders with limited space.
10. *Storage of the device is difficult.* For elders who own many devices, some of which may be large and only used some of the time, storage is often an issue. For example, a wheelchair that is only used on trips beyond the home requires storage space when not in use.
11. *Person does not know how to use the device.* Training is an important issue with many assistive devices, yet all too often training is not provided. One elder reported that he did not use his back brace because he did not know how to put it on. Setup of the device is also an issue for some devices, requiring expertise that may not have been available when the device was purchased.
12. *Device is difficult to use.* In some cases the device may always have been difficult to use. In other cases, declines in physical or cognitive performance may have rendered a once-satisfactory device difficult to use. Devices with electronic controls are often difficult to manipulate, and it may be difficult to see the settings. Manual hospital beds are difficult for some individuals to crank. One elder reported difficulty in using an electric can opener. Many elders report that their canes are too heavy, making them difficult to use. Another elder with severe low vision reported difficulty using a check-writing guide.
13. *Use of the device requires assistance from another person.* Devices that involve mobility and transfers are often used by elders with another person assisting. While this is not necessarily a problem if there is someone nearby to assist, many elders would prefer to do the task independently. For toileting and bathing, privacy is often an issue.
14. *Device was not installed properly.* This is a common problem with grab bars, reported by Consumer Assessments Study participants as “very wobbly,” “loosened at rear and unable to repair,” “loosens up occasionally,” and “not positioned properly to facilitate transfer out of the tub.” Grab bars require

professional guidance in their placement, and they need to be installed by skilled workers.

These categories underline the importance of consumer involvement in the selection of devices, along with the need for current information on the kinds of devices and device features that are available. The large number of device problems also supports the need for, at a minimum, professional consultation prior to selecting devices. In many cases, especially with older persons who face multiple chronic conditions and impairments, beyond consultation there is a need for careful professional assessment, provision of the devices, training, and follow-up. Follow-up should monitor not only changing needs of the individual, but the maintenance of the devices.

Consumer Perspective on Assistive Technology: High-Technology Devices

The University of Florida Rehabilitation Engineering Research Center on Technology and Aging recently completed a survey of adults with disabilities, and older persons with disabilities, looking at “needs and barriers” to technology-related devices. Articles about this study focus on specific electronic device types: computers, smart phones, personal emergency response systems, traditional phones, personal digital assistants, and home monitoring devices.^{26,27}

Several studies have demonstrated ways in which computers can benefit older persons: mental stimulation and increased competence and feeling of autonomy²⁸; a sense of satisfaction, reduced loneliness, and improved sense of well-being²⁹; increased social interaction through email and interactive websites³⁰; and improved memory, as well as more comfort with using a computer through playing games on a computer.^{31,32} There are many web-based support services for psychosocial support and health-related information for older persons and their caregivers.³³

The RERC on Technology and Aging contacted 598 older persons with disabilities (over age 60) and 70 adults with disabilities under age 60 to determine their perspective on the needs and barriers related to computer use. Study participants from western New York, southern California, and northern Florida were interviewed either in their home or by phone. We also sought participants from across the United States through a mailed survey, with both computer users and nonusers participating. We found that only a relatively small percentage of computer users were not satisfied with their computer, and most of those who had computers had internet access. Maintaining contact with others was a very important reason for using a computer for both older and younger adults with disabilities. Many computer users reported discomfort and pain when they used their computer, but only a few viewed their impairment(s) as barriers to computer ownership or use. Nonusers of computers stated a high interest in using a computer, with a large number stating that cost was the major barrier for them. The need for assessment and advice on workstation and computer setup seems evident from the large number in both groups reporting discomfort and problems in using the computer.

Consumer Participation and Feedback at ICADI

Unless consumers are included in the research and design process, we may not create the useful assistive technology we imagined. Consumers are those older people with disabilities who buy and use the assistive devices and related services that we develop and on which our research is based. In planning ICADI, we sought consumer involvement and invited 10 consumers to attend ICADI and provide feedback through a focus group held immediately after the Conference. The following section reports the ICADI consumer experience.

The 10 consumer participants attended ICADI sessions and provided feedback on the usefulness of the information, and research direction, discussed in the presentations they attended. They also provided feedback on the experience of attending a professional conference, and how consumer participation could be enhanced at similar conferences, providing excellent strategies for improving the communication between consumers and investigators/presenters.

Consumers described the ICADI research conference as very interesting and important to their lives. The terms that participants used to describe their experiences with the conference were “fantastic, educational, intriguing, positive, optimistic, and supportive.” As one participant noted, “sometimes we, people with disabilities, feel like we are alone out there. It was very important to know that we are not alone and that other people are really caring and thinking about how to help us to live better lives.” The conference also increased knowledge of options for elderly individuals and people with disabilities.

Evaluating the usefulness of the new information, consumers reported that knowledge provided through the conference created in them positive expectations. They considered it to be one of the most important contributions to their day-to-day activities knowing that ongoing research creates a foundation for future disability-related products and services. One participant commented that she was “overwhelmed with how the young and older researchers are trying to make our lives better.” This research knowledge is necessary for maintaining an independent life style and remaining self-sufficient as long as possible. Although some participants felt that most of the new knowledge can not be used immediately in their everyday life, this new information can help them to understand how to cope with their disability-related problems in the near future. Another participant added, “new information is important for long-term planning.”

Language and Format of Presentation

The way of presenting information and the format of the presentations themselves were extensively discussed by the focus group participants. Although the research jargon used by some presenters was a barrier for consumers, they agreed that it was not a complete obstacle for learning about some interesting facts. Participants had a somewhat lengthy discussion about the conflicting needs of researchers and consumers, particularly at conferences such as the current one. Consumers recognized the need for researchers at times to spend time talking with other researchers. One participant recommended some consideration of a separate track geared toward consumers and oriented toward “end-user” applications of research.

Consumers were concerned with the lack of presentation handouts. As one of the consumers reported, she had to take a lot of notes trying to document the knowledge that she wanted to share later. (This participant works in a church as a volunteer helping more than 160 people who have disabilities themselves or are involved with their disabled friends and relatives.) Participants decided to recommend to the conference committee that they pay special attention to the availability of printed materials (handouts) accompanying the oral presentations. At the conference itself, they recommended that provisions be made for persons with hearing impairments or diminished eyesight. For example, small print should not be used in PowerPoint presentations.

Consumers also raised a concern that the language and the attitude with regard to persons with disabilities are patronizing in general. Several participants commented on the use of some terms associated with aging and disability (e.g., “frail elderly” or “caregiver”). These terms have mostly negative connotations in the disability community because they “give no credit and no power to the person who is aged or receiving the care.” For example, “assistant may be a better word than caregiver.” One participant indicated that it was disappointing to be referred to as her husband’s “caregiver” rather than his “wife.” However, consumers also noted that the ICADI conference showed that there is a dramatic positive change underway. The language and terms used throughout the conference reflected a paradigm change from institutional care to community living and empowerment.

Role of Consumers in a Research Conference

Discussing the question of why it is important for consumers to participate in such conferences, the answer was simply: “how else are researchers going to know what persons with disabilities need if you do not ask them (us)?” Participants suggested that there should be more consumers participating in the research conferences, sharing their problems and giving suggestions and concerns to the research community. Researchers need to know how the results of their studies and their products affect disabled persons themselves. At the same time, one consumer noted that, “there is a hunger among elderly disabled people to know what the research community is doing. There really is a market out there for us—consumers.”

Consumers are the practical experts who need to be involved with all stages of the research process. They themselves have more first hand knowledge about the specific problems that surround disability conditions than most other people, including researchers. An important role of consumers participating in the research conference was to see how useful this research is from their perspective. Consumers do not deal with the research protocols; they live in the natural setting and therefore have an experience of implementing research applications in real-life situations.

Factors That Influence Effectiveness of Consumer-Researcher Communication

Consumers’ participation in research conferences was considered to be one of the major factors that influenced consumer-researcher communication. It is necessary “to make one’s voice be heard by the researchers.”

Effective communication between consumers and researchers is closely associated with how scientists themselves perceive the role of people with disabilities in the research process. It is also important to learn how this new role of consumers as rightful research collaborators is perceived by non-disabled people and by society in general.

Having an expanded pre-conference discussion with the participation of both consumers and researchers–presenters might provide consumers with more detailed information on how to identify presentations that fit their needs.

Recommendations for Future Disability Research Conferences

Recommendations for agendas of future conferences centered on the effectiveness of the interactions among consumers, researchers, and disability specialists, as well as the problem of dissemination of the research knowledge.

To enhance and develop the conference agenda, it seems reasonable to organize a pre-conference workshop with the consumers where the focus of the upcoming conference and the most important questions will be discussed from the consumers' point of view. Consumers need to be involved in developing the conference agenda from the very beginning, and then through every stage of the conference preparation.

To provide researchers with important feedback, a consumer track at the conference should include presentations made by consumers. Participation of medical practitioners, who work in the disability field together with the researchers and consumers, may provide an opportunity to discuss critical issues from different angles.

The issue of the dissemination of conference materials among the disability community was most important. "Where do we go from here?" was the question that participant–consumers raised again and again throughout the focus group discussion. One participant mentioned that she would return home and search for places to share the information that she received from this conference at her local level.

Accessibility of the disability-related research to the rest of the disability community is still a problem. As one participant noted, "there are a lot of other consumers who are not aware of events like this and do not have access to this kind of information." A lot of this very exciting research-based knowledge is not known at all to the majority of disabled consumers. Focus group participants provided advice on involving the news media in covering the results of the conference and at the same time expressed their willingness to pass the knowledge which they have learned to the people they know, both consumers and caregivers. As one consumer explained it, "ten years ago I did not know about existing possibilities, and even recently I was not aware of many things and information that is available now; so I intend to pass the information that I have learned during this conference to the people with disabilities and caregivers that I know."

One participant also suggested having a political session at the conference where representatives from various governmental agencies would discuss policies that affect the lives of persons with disabilities.

Participants' Overall Conclusions and Recommendations

- Information presented at the ICADI conference is of a great practical importance. It creates positive expectations and promotes positive attitudes toward independent life styles.
- The research conference on disability, despite its professional orientation, plays an educational role for nonprofessionals (i.e., consumers), helping them to build coping resources necessary for disability maintenance.
- Focus group participants will share information on disability research with their communities—caregivers, support groups, specialized societies, and other persons with disabilities who live in their communities.
- Informal communication between researchers and consumers before and during the conference (e.g., informal workshops) should be encouraged, together with the formal participation of consumers and caregivers in professional events.
- The conference committee should pay special attention to the availability of printed materials (handouts) that accompany oral presentations during the conference.
- News media may play an important role in informing local communities about the planned events, as well as in informing persons with disabilities about the results of the conference.
- Dissemination of the research information to the local communities through their representatives participating in the conference needs to be planned in advance.
- The disability community needs access to the research information collected through the conference. The information should be available in accessible forms such as printed materials with large fonts and a user-friendly web site.
- Results of this focus group should be sent to the participants and their local communities in printed form.

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