

Demographics of Wheeled Mobility Device Users

By

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Introduction

Assistive mobility devices—including wheelchairs, scooters, canes, crutches, and walkers—are effective ways to alleviate the impact of mobility limitations for many people, permitting more efficient ambulation over long and short distances, increased independence and the promise of full participation in community life.

The use of assistive devices increases with age, and because the U.S. population is aging, the use of assistive devices is of ever increasing importance. Increased use of assistive technology may have helped reduce disability at older ages (Manton, Corder, and Stallard, 1993), based on data from the National Long Term Care Survey. However, a recent review of national surveys does not corroborate a decline in ADL level disability at the older ages (Freedman, Martin and Schoeni, 2002), but does conclude that the rate of functional limitations, such as walking a quarter mile, has declined in the older population.

Although mobility device users represent only a relatively small minority of the population with disabilities, their importance transcends their numbers. Mobility devices, especially wheelchairs, are visible signs of disability and have become symbols in themselves of the very idea of disability. Understanding the magnitude and characteristics of the population using assistive technologies is therefore of particular importance, as well as understanding how the technologies are used. For mobility devices to be used effectively, the environments in which they are used must be physically accessible.

This paper focuses on the population using wheeled mobility devices—wheelchairs and scooters—and trends over time. It provides a profile of their demographic characteristics; health and disability status, including diagnoses and impairments and physical functioning, health insurance status, and unmet needs using the latest available published information supplemented with some original analysis. The accessibility of mobility device users' homes and larger environments is also discussed, demonstrating that improvements in physical accessibility must remain a priority for millions of mobility device users who continue to experience accessibility barriers, as of 1997.

Trends in use of wheeled mobility devices

Substantial growth in the population using wheelchairs and scooters is evident at the end of the 20th Century. Based on data collected in the National Health Interview Survey (NHIS), a large-scale national survey which has been collecting health data continuously since 1957, we know that the population using wheelchairs has quadrupled from 409,000 in 1969 to 1.7 million persons in 1995 (Table 1).

Table 1. Number of Persons Using Wheelchairs: United States 1969-1995

	1969	1977	1990	1995	Ratio 1995: 1969
Age group					
6 and over	409	645	1411	1679	4.11
6-64	194	310	611	746	3.85
65+	215	334	800	933	4.34

Data source: National Health Interview Survey

Wilder, CS. 1980. Use of Special Aids: United States -1969. Vital Health Stat 10(78): 1-23.

Black, ER. 1980. Use of Special Aids: United States -1997. Vital Health Stat 10(135): 1-40.

Kaye, HS, Kang, T, LaPlante, MP. 2000. Mobility Device Use in the United States.

Disability Statistics Report (14): 1-60. Washington, DC: US Dept Education, NIDRR. (includes scooters)

LaPlante, MP, Hendershot, GE, Moss, AJ. 1992. Assistive Technology Devices and Home Accessibility Features:

Prevalence, Payment, Need, and Trends. Advance Data (217).

Similar trends have been documented using the Census Bureau's Survey of Income and Program Participation, from which it is estimated that 2.2 million people ages 15 and older used wheelchairs and electric scooters in 1997 and 2.3 million in 1999 (McNeil, MMWR). This compares to only 1.5 million in 1992 (Table 2). The growth in wheelchair users has occurred over and above the growth of the total population (Table 3). While there are differences between the surveys, the SIPP figure of 2.3 million wheelchair users implies that the population using wheelchairs has almost sextupled during the last three decades of the twentieth century. The NHIS and the SIPP are the two principal national surveys that provide information on wheeled mobility device use.

Scooter use, though relatively low in prevalence, may also be increasing fast. According to the NHIS, the population using scooters was 64,000 in 1990 and 140,000 in 1994 (Russell, Hendershot, LeClere, Howie, and Adler, 1997). Electric scooters are a relatively

Table 2. Number of Persons Using Wheelchairs: United States 1991-1999

	Oct91-Jan92	Oct94-Jan95	Aug-Nov97	Aug-Nov99	Ratio 1999: 1992
Age group					
6 and over	1494	1812	2155	2283	1.53
6-64	529	NA	938	1012	1.91
65+	965	NA	1216	1271	1.32

Data source: U.S. Census Bureau Survey of Income and Program Participation

McNeil, JM. 1993. Americans with Disabilities: 1991-92. U.S. Bureau of the Census, Current Population Reports, P70-33 (ages 15 and older)

McNeil, JM. 1997. Americans with Disabilities: 1994-95. U.S. Bureau of the Census, Current Population Reports, P70-61 (ages 6 and older)

McNeil, JM. 2001. Americans with Disabilities: 1997. U.S. Bureau of the Census, Current Population Reports, P70-73 (ages 15 and older)

McNeil, JM. 2001. Prevalence of Disabilities and Associated Health Conditions Among Adults —

United States, 1999. MMWR 50(7): 120-125. (ages 18 and older)

Table 3. Percentage of Persons Using Wheelchairs: United States 1991-1999

	Oct91-Jan92	Oct94-Jan95	Aug-Nov97	Aug-Nov99	Ratio 1999: 1992
Age group					
6 and over	0.8	0.8	1.0	1.1	1.4
6-64	0.3	NA	0.5	0.6	2.0
65+	3.1	NA	3.8	3.9	1.3

Data source: U.S. Census Bureau Survey of Income and Program Participation

McNeil, JM. 1993. Americans with Disabilities: 1991-92. U.S. Bureau of the Census, Current Population Reports, P70-33 (ages 15 and older)

McNeil, JM. 1997. Americans with Disabilities: 1994-95. U.S. Bureau of the Census, Current Population Reports, P70-61 (ages 6 and older)

McNeil, JM. 2001. Americans with Disabilities: 1997. U.S. Bureau of the Census, Current Population Reports, P70-73 (ages 15 and older)

McNeil, JM. 2001. Prevalence of Disabilities and Associated Health Conditions Among Adults —

United States, 1999. MMWR 50(7): 120-125. (ages 18 and older)

recent mobility technology¹, and the NHIS did not ask about scooter use prior to 1990. The SIPP does not separately identify wheelchair users by powered or not, nor wheelchair users from scooter users.

Despite the growth in the population using wheeled mobility devices, there is no strong evidence that mobility impairments have increased. During the time that wheelchair use has increased by more than 25 percent from 1992 to 1997 (Table 3), the fraction of persons unable to walk a quarter mile has remained the same at 4.6 to 4.7 percent (Table 4). There may be a small increase in inability to walk longer distances in the working age population, but at the same time, the data show a slight decline in the elderly, as mentioned earlier (Freedman and Martin, 1998).

While the aging of the population will certainly have a future impact on mobility device use, the growth in the use of these devices that has occurred has vastly exceeded what can be attributed to population aging (Russell, Hendershot, LeClere, Howie, and Adler, 1997). What other reasons lie behind this growth? Improved trauma survival may have contributed to the growth in mobility device use to a small degree. If this was a large effect, however, the population with mobility limitations would be rising in the working ages, which it has done only by a small degree, if at all. Since there is no evidence of

Table 4. Percent of Persons Unable to Walk A Quarter Mile: United States 1991-1999

	Oct91-Jan92	Aug-Nov97	Ratio 1997: 1992
Age group			
6 and over	4.6	4.7	1.0
6-64	2.0	2.3	1.2
65+	18.7	18.3	1.0

Persons 15 years and older.

Data source: U.S. Census Bureau Survey of Income and Program Participation

McNeil, JM. 1993. Americans with Disabilities: 1991-92. U.S. Bureau of the Census, Current Population Reports, P70-33 (ages 15 and older)

McNeil, JM. 1997. Americans with Disabilities: 1994-95. U.S. Bureau of the Census, Current Population Reports, P70-61 (ages 6 and older)

McNeil, JM. 2001. Americans with Disabilities: 1997. U.S. Bureau of the Census, Current Population Reports, P70-73 (ages 15 and older)

McNeil, JM. 2001. Prevalence of Disabilities and Associated Health Conditions Among Adults —

United States, 1999. MMWR 50(7): 120-125. (ages 18 and older)

¹ The first commercial electric wheelchair was introduced in 1956 by Everest and Jennings. The Amigo company is generally acknowledged for introducing the first electric scooter in 1968.

rising levels of mobility impairment, the growth in use of wheeled mobility devices is more likely due to changing social and technological factors. Significant improvements in the design of mobility devices, both in function and image, have made wheeled mobility devices more appealing. Improved accessibility both at home and in the community may have enabled wheeled mobility devices to be used by more people. With more people using wheeled mobility devices, the stigma associated with them has no doubt lessened as well.

How is the growth in wheeled mobility devices use related to age? It is not clear whether the growth in wheeled mobility devices has been larger among nonelderly than elderly persons. According to data from the NHIS, wheelchair use has grown slightly more among the elderly (Table 1). However, based on the SIPP data, from 1992 to 1999, wheelchair use has increased by 90 percent among nonelderly persons and only 30 percent among the elderly (Table 2). Perhaps, after ADA, there has been a more rapid growth in wheelchair use by nonelderly persons, but that will need to be reevaluated as additional data becomes available.

Powered wheeled mobility devices in use

The NHIS-D distinguishes between manual and electric wheelchairs, revealing powered users to be a small minority. Of the 1.7 million adults who use wheeled mobility devices, only 155,000 use electric wheelchairs, and 142,000 use scooters. Altogether, some 291,000 use either (or both). Thus, only 17 percent of wheeled mobility device users actually use electric chairs or scooters with the vast majority using manual chairs.

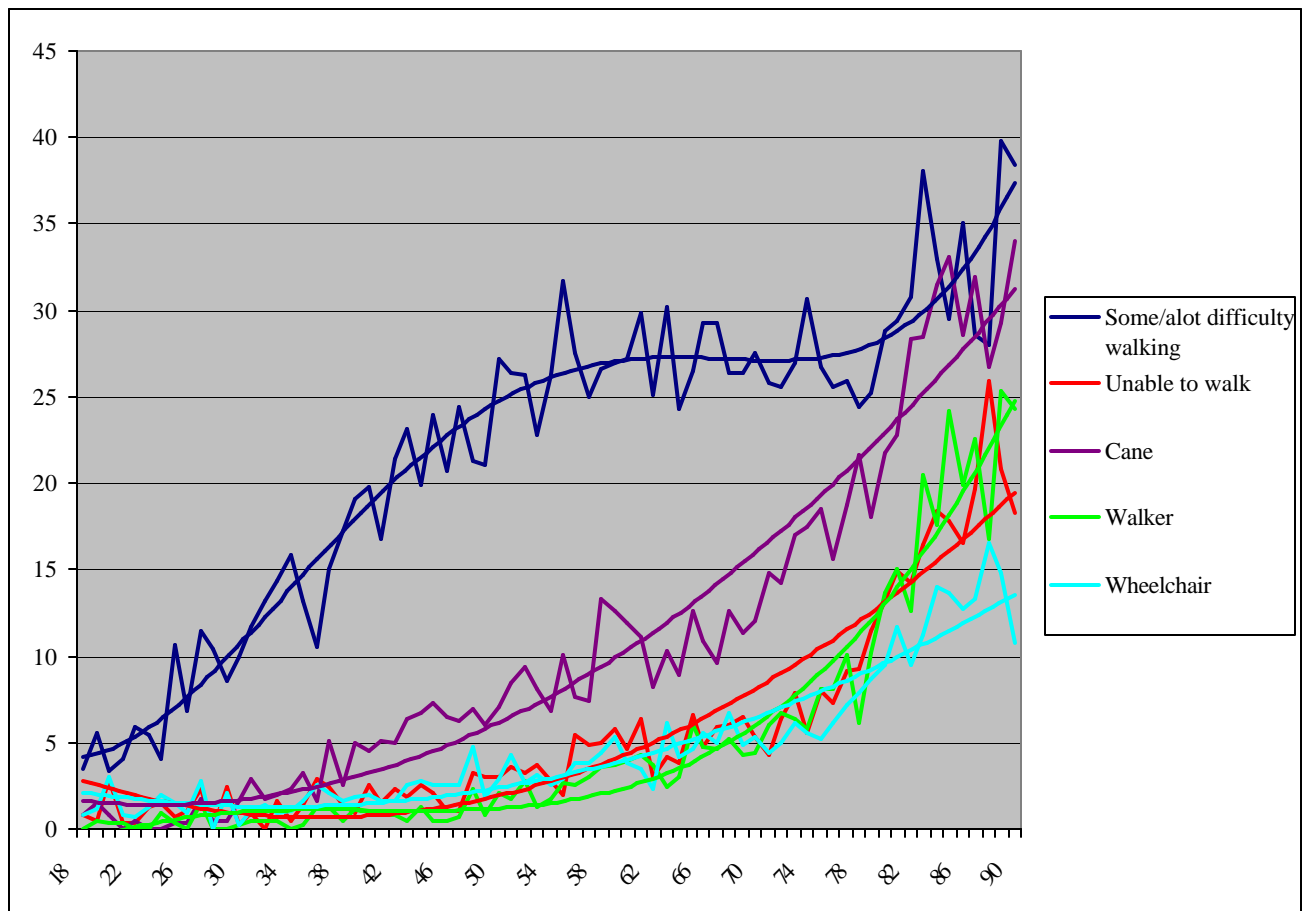
Demographics

Age

Users of wheeled mobility devices are slightly more likely to be elderly. In the NHIS-D, 933,000 are ages 65 and over out of 1.7 million, or 55.6 percent of all users. The percentage is exactly the same in the SIPP. However, users of electric wheelchairs are more likely to be nonelderly (70%) as are users of scooters, although only 54.9 percent are nonelderly.

The use of wheeled mobility devices increases with age (Figure 1), but not as fast as canes and walkers. Over a quarter of persons ages 85 and older, the “oldest-old,” use canes, and about 15 percent use walkers. Only 7 percent use wheeled mobility devices (Kaye, Kang, and LaPlante, 2000).

Figure 1. Proportion of the population unable to or having some difficulty walking by themselves, and use of assistive devices, by age: United States 1995-1997



Source: National Health Interview Survey on Disability, 1994-1997. Phase 2 data.

There is something of a bias against using wheeled mobility devices at older ages. Many older people struggle with canes and walkers when wheeled mobility devices could be more helpful and efficient. The stigma of the association of wheelchairs with institutionalization among the elderly may be responsible.

The relevant measure for predicting use of wheeled mobility devices is whether a person is able to ambulate on her own, without help from another person and without using other assistive technology. The NHIS-D includes one relevant measure, based on a two part question. “*Because of a health or physical problem, do you have any difficulty walking?*” followed with: “*By yourself and without using special equipment, how much difficulty do you have walking, some, a lot, or are you unable to do it?*”

We have used this measure to plot the fraction of the population with difficulty walking by age (Figure 1). The fraction of the population that has some or a lot of difficulty walking does not track with the rate of using wheeled mobility devices (these two

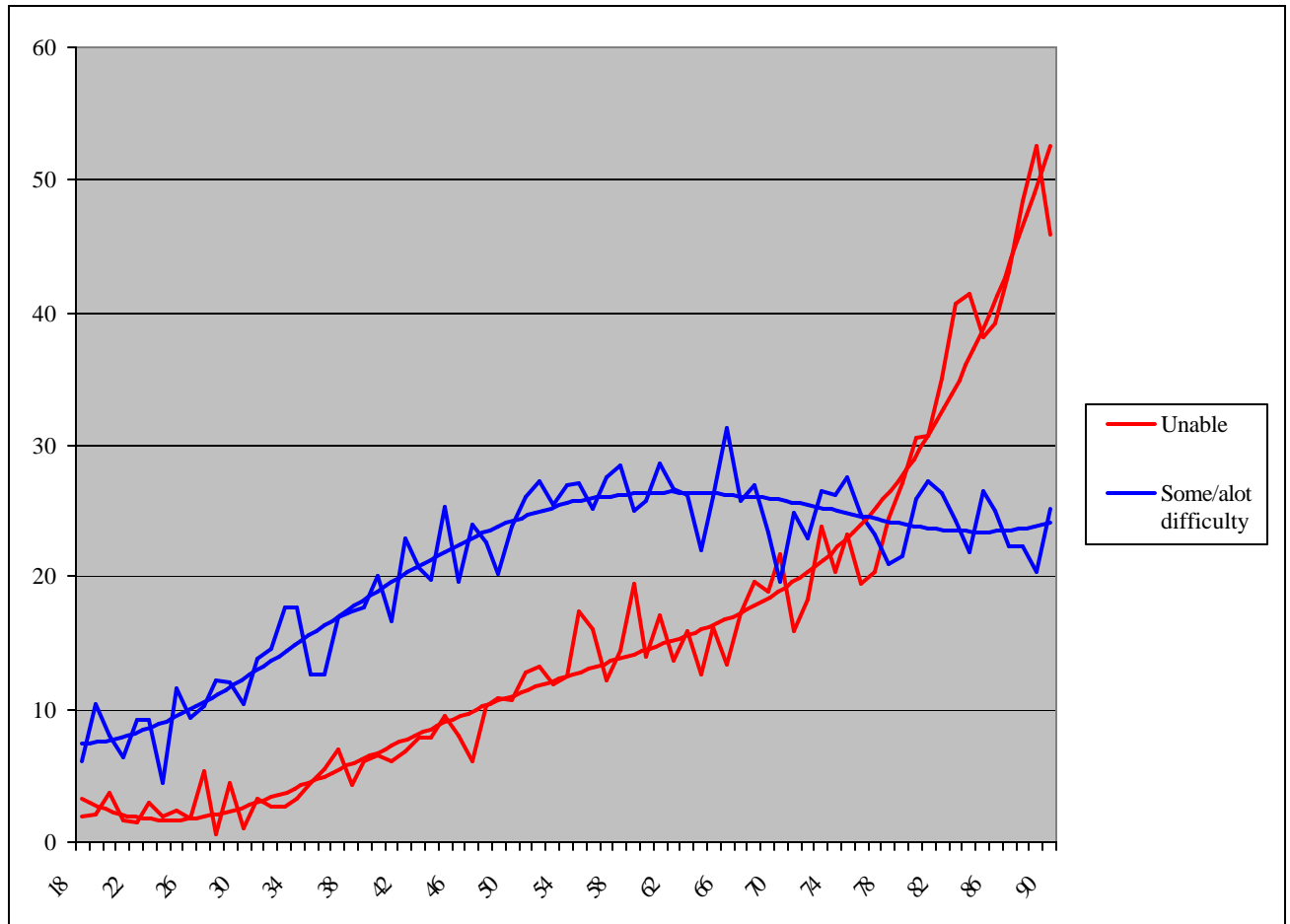
categories are combined in the graph since they have similar patterns by age). However, the trend in inability to walk with age does track more closely with the use of wheeled mobility devices. Difficulty walking occurs much earlier in life than inability to walk, reaching a plateau of 27 percent by age 50, after which the fraction remains the same until around age 75, when the fraction of the population with difficulty begins to rise again. Thus, it is generally the inability to walk that is related to the increase in the use of wheeled mobility devices with age, not difficulty walking.

The “walking at all” question proves in practice to be too vague. Part of the reason that difficulty walking increases early in life is that younger people seem to be thinking about walking longer distances. Older people, however, seem to be thinking about walking short distances. This is illustrated by comparing Figures 1 and 2. Of people who are around 50 years old, the proportions saying they have some difficulty “walking” and “walking a quarter mile” are the same at about 27 percent. Among the elderly, however, the proportion unable to walk a quarter mile exceeds 50 percent by age 90, whereas the proportion unable to “walk” is about 20 percent. These two questions mean the same thing to the nonelderly, but to the elderly they are very different indeed.

Now it is appropriate to discuss projections of wheeled mobility devices use. Certainly, the ability to walk declines with age. But extrapolating from the future aging of the population to future rates of mobility impairment and future use of wheeled mobility devices poses a problem: which measures of mobility impairment to use?

National surveys ask a number of mobility items relevant to wheeled mobility devices use. The NHIS-D includes questions about walking at all, getting around inside the home, getting in and out of bed or chairs, using the toilet including getting to the toilet, getting outside, getting to places outside of walking distance, walking a quarter mile, walking up 10 steps without resting, and standing for 20 minutes or two hours. All these measures refer to the person in the “naked state,” doing the activity alone, without help and without assistive devices. However, the questions refer to different thresholds of problems walking (a quarter mile or getting around inside the home), different time periods (20 minutes or 2 hours), and include other environmental elements, such as using transportation (which is necessary to get to places outside of walking distance). Many, if not most, of these measures are related to wheeled mobility devices use, but none is sufficient on its own.

Figure 2. Proportion of the population unable to walk or having some difficulty walking by themselves *one-quarter mile*, by age: United States 1995-1997



Besides walking, there are other functional issues that are relevant to an individual’s choice to use one among several possible assistive devices, including the use of their arms for reaching and support, and grasping ability. Limitations in these other functional areas may make a wheelchair more practical to use than a cane or walker. Inability to turn wheels on a manual chair may leave no choice but to use an electric wheelchair or scooter. Such additional “risk factors” for use of wheeled mobility devices need to be further studied, and the relationships to wheeled mobility devices better specified, a task that is beyond the scope of this paper. (In a preliminary multivariate model, inability to walk a quarter mile appears to be the best predictor of wheeled mobility devices use, particularly among the nonelderly, but there are many other significant predictors, including reaching and grasping functions).

One must admit that the relationships between age, mobility impairment, and type of mobility impairment, and wheeled mobility devices and type of wheeled mobility devices are uncertain. Furthermore, one major predictor of use of wheeled mobility devices, being unable to walk a quarter mile, appears to be declining in the elderly. This only

reinforces the impression that much of the growth in use of wheeled mobility devices appears to be due to social and technological factors. Because these factors are not well known, drawing out the implications of the aging of the population for wheeled mobility devices use remains uncertain. To be sure, the advance of the 76 million baby boomers into the older ranks will propel use of wheeled mobility devices even faster than it has grown in the past. As younger cohorts with better understanding of disability and the place of people with disabilities in society replace older ones with different views, stigma against using wheeled mobility devices may decline. Segways, powered mobility devices, and Ibots may be adopted more readily by aging baby boomers and fuel growth at an even faster pace than has been observed in the past.

Perhaps the best projection is a simple extrapolation from past trends. In that case, the rate of growth from 1969 to 1999 has been 5.9 percent per year. At that rate, by 2010, when the leading edge of the baby boom generation reaches 65 years old, we would expect to see 4.3 million users of wheeled mobility devices.

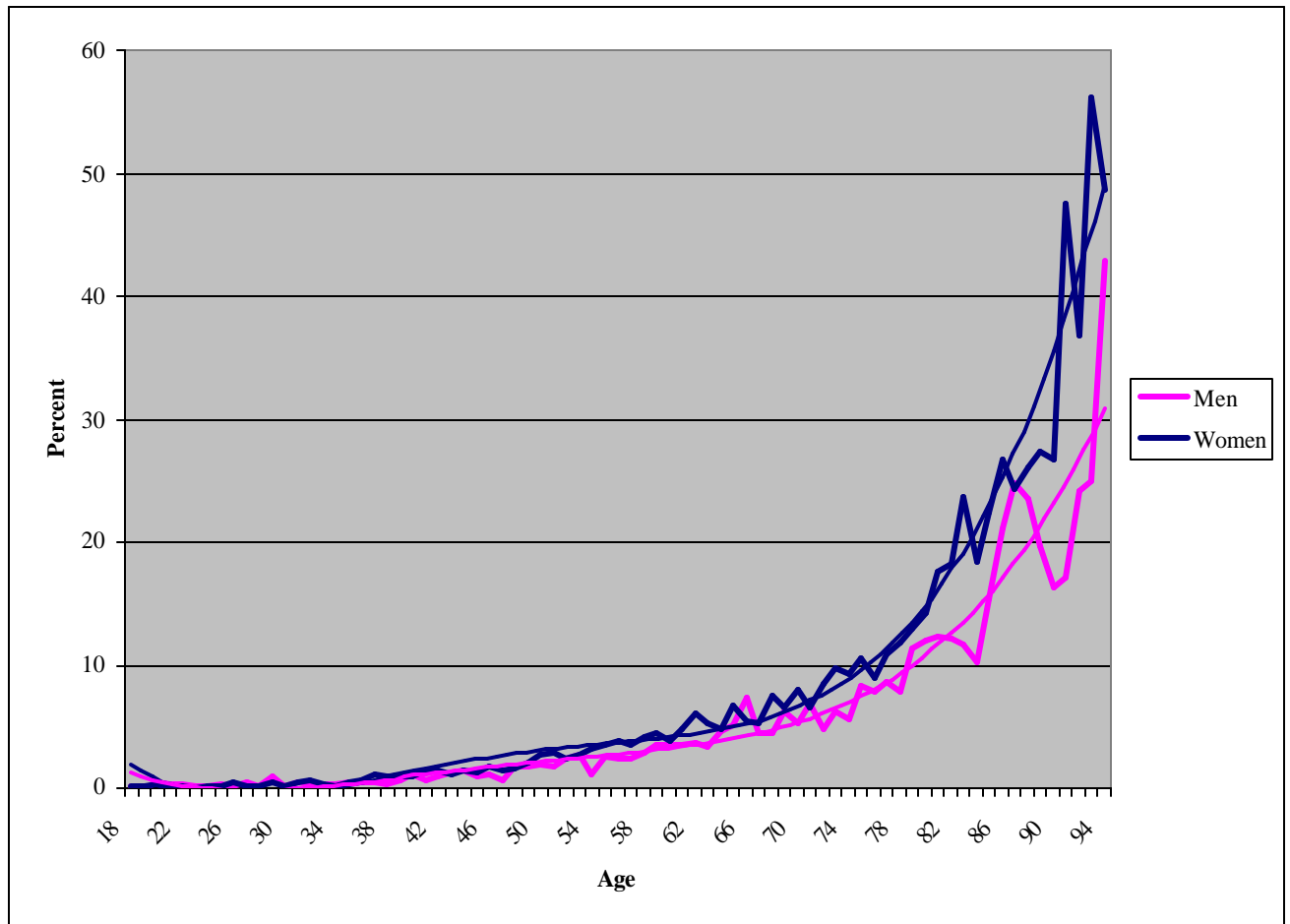
Gender

More females use wheeled mobility devices than men. In 1995, the rate of male use of wheelchairs was 5.5 per 1,000 persons, whereas female use was 7 per 1,000 (Kaye, Kang, and LaPlante, 2000). The rates of wheelchair use among men ages 18-44 is actually higher than that among women, but after age 44, the rates are higher for women than men. Thus, part of the higher use of wheeled mobility devices by women is due to their older age as a population group, but there is a tendency for women to have higher rates of use regardless of age. This is likely due in part to higher rates of mobility impairment among women (Figure 3).

Race and ethnicity

Rates of use of wheeled mobility devices parallel rates of disability in general and mobility impairment in particular. About 8 in 1000 Native Americans use wheelchairs, followed by 6 in 1000 Whites and the same for African Americans, compared to 4 in 1000 Asian Americans. Use of wheelchairs is as low for persons of Hispanic origin at 4 per 1000 compared to 6 per 1000 for persons not of Hispanic origin.

Figure 3. Proportion of the population unable to walk by themselves *one-quarter mile*, by age and gender: United States 1995-1997



These differences are also partly due to differences in rates of mobility impairment. It remains an analytic issue to what extent there remains any significant differences in rates of mobility limitation once mobility impairment are taken into account.

Health and functional limitation

As would probably be expected by most readers, almost all those who use wheelchairs have mobility limitations. More than three-quarters of people who use wheelchairs are unable to walk a quarter mile, and over 60 percent are unable to climb stairs or stand for 20 minutes, and almost 60 percent are unable to “walk” (per the general question) by themselves without assistance. Ninety four percent have at least some difficulty walking a quarter mile by themselves.

While almost all people who use wheeled mobility devices have some kind of mobility limitation, not everyone with a serious mobility limitation uses wheeled mobility devices. The fraction of people using wheeled mobility devices increases with the severity of walking difficulty (the general question), from 10 percent of those with some difficulty,

to 23 percent of people with a lot of difficulty walking, to 58 percent of people who are unable to walk on their own without assistance. The fraction of people who cannot walk a quarter mile who use wheeled mobility devices is 63 percent. However, if we include canes, walkers, and wheelchairs, then the fraction of those who cannot walk a quarter mile on their own who use any of these devices reaches 85 percent, and if we include whether they get help from another person getting around inside their homes, the fraction rises to 97 percent.

A low fraction of people who use wheeled mobility devices enjoy good health. The self-rated health of people using wheeled mobility devices is generally poor. Only 11.9 percent of wheelchair users and 11.2 percent of scooter users rate their health as very good to excellent, whereas 67.6 percent of people who do not use a mobility device (wheeled mobility devices or canes, crutches, and walkers) rate their health so positively (Kaye, Kang, and LaPlante, 2000). Around 40 percent of Wheeled mobility device users rate their health as poor compared to 2.0 percent of those who do not use a mobility device. Gaps in health between users and non-users of wheeled mobility devices are slightly larger in the nonelderly population than the elderly.

People who use wheeled mobility devices or walkers are seven times as likely to have been hospitalized in the past year. Over 43 percent of wheelchair users were hospitalized in the past year, and 34 percent of scooter users. There are no differences in rates of hospitalization between nonelderly and elderly Wheeled mobility device users. Thus, people who use wheeled mobility devices are generally of poor health with history of hospitalization and ongoing use of health care services.

Perceived disability

About 85 percent of wheelchair users and 90 percent of scooter users perceive themselves or believe that others perceive them as having a disability. These rates are the highest among the various mobility devices, and among the highest of all disability diagnostic categories. But there are significant differences by age: 78 percent of nonelderly Wheeled mobility device users have a perception of having a disability, whereas only 61 percent of elderly users do.

Diagnoses

The most prevalent conditions cited as causing mobility limitations among wheelchair and scooter users are arthritis (13%), stroke (11%), and multiple sclerosis (5%). Paralysis and orthopedic impairments are also common. MS and paralysis are most prevalent among nonelderly wheelchair users, whereas arthritis and stroke are most prevalent in elderly wheelchair users. In both groups, there are many low prevalence conditions that are involved.

Financial resources

Wheeled mobility devices can be expensive. Although a hospital version manual chair may cost only a few hundred dollars, a lightweight or ultralite manual chair costs at least \$1500, and high end electric wheelchairs can exceed \$20,000.

While reimbursement options may have become more available, it remains the case that about half of people or their families pay for devices solely on their own (LaPlante, Hendershot, and Moss, 1992). Users of wheeled mobility devices and their families manage to do this, despite having low financial resources.

Few people who use wheeled mobility devices work. Among those 18-64 years old, only 17-18 percent are employed. Not only does this mean that the personal income of users of wheeled mobility devices is low, it in turn affects the income of their families. The result is that many users of wheeled mobility devices are poor. In the working ages, 23 percent of wheelchair users live below the poverty line, double that of the general population. The cost of wheeled mobility devices, combined with low financial resources of people who need them, appears to result in substantial unmet need.

People who use wheeled mobility devices are actually less likely than the general population to be uninsured. Among those of working ages, 9.5 percent of wheelchair users and 11.3 percent of scooter users are uninsured, compared to 19.3 percent of all persons in that age group. Working age Wheeled mobility device users have high rates of Medicare and Medicaid coverage.

Unmet need

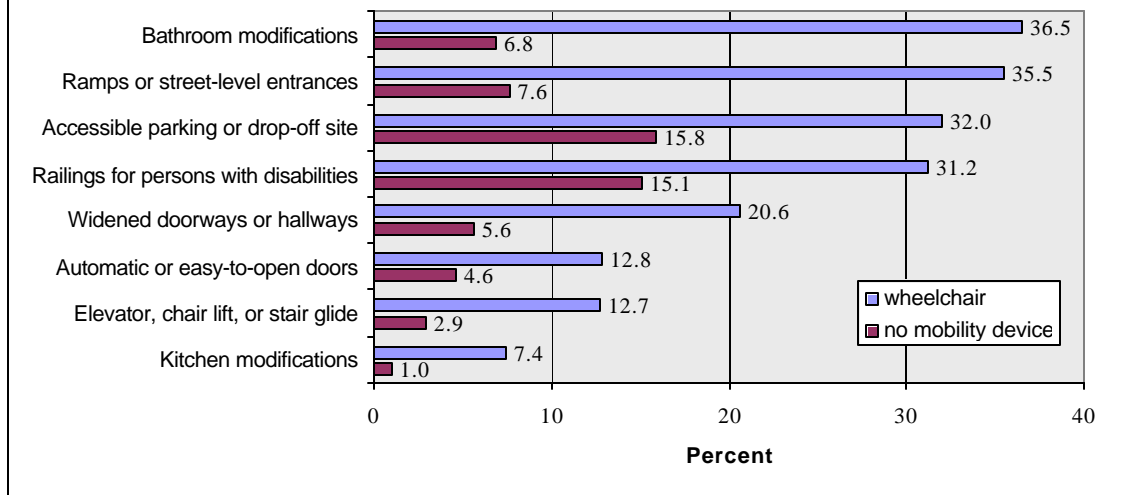
Unmet need for assistive technology devices is substantial. In 1990, 2.5 million people needed assistive technology devices they did not have, one person for every five people using assistive devices (LaPlante, Hendershot, and Moss, 1992). The main reasons that people do not have devices they need are that the costs are not covered by the insurance they are enrolled in and they cannot afford them out of pocket.

Home accessibility features

In the NHIS Disability Followback Survey, questions were asked about features that make it possible for people with mobility impairments and users of wheeled mobility devices to get around and use their homes more easily and effectively. The DFS applies to people who were screened to have a disability in Phase 1 of the NHIS-D, using an extensive set of variables and decision rules (LaPlante and Kang, 2000). We compare those who use wheeled mobility devices to people with disabilities who do not use mobility devices.

Considering the floorplan of homes, among people who use wheelchairs or scooters, about one third live in homes that are entirely on one floor, compared to 44 percent of people with disabilities who do not use any mobility devices. Most people with disabilities live in homes with a bedroom, bathroom, and kitchen on one floor: 78.4 percent of wheelchair users, 88.5 percent of scooter users, and 85.5 percent of persons

Figure 4. Home accessibility features present among wheelchair and persons with disabilities not using mobility devices, ages 18 and over



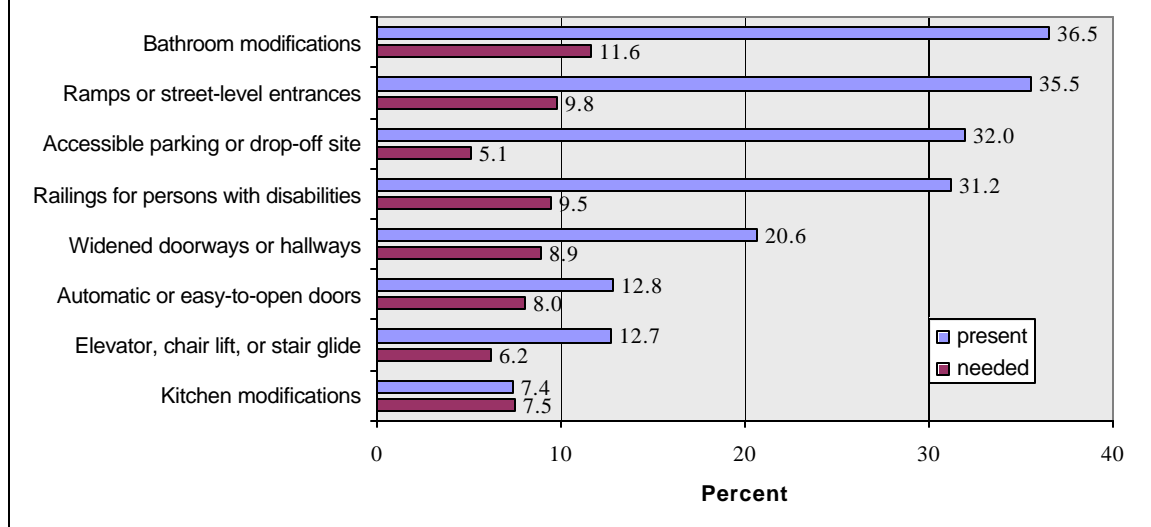
with disabilities who do not use a mobility device. In terms of the floor layout of homes, users of wheeled mobility devices are certainly no better advantaged than others, and, perhaps slightly disadvantaged.

Accessibility features, including ramps, are much more prevalent among users of wheeled mobility devices than people with disabilities who do not use mobility devices (Figure 4). Among non-users of mobility devices, the most common features are accessible parking or drop-off and railings. Wheelchair users, with almost a third having accessible parking or railings, are twice as likely to have them present in their residences. Ramps and bathroom modifications are even more frequently present among wheelchair users, with slightly more than a third having such features, four times that of non-users of mobility devices. One in five wheelchair users have widened doorways or hallways, four times that of non-users of mobility devices, about 13 percent have automatic or assisted doors or elevators (3 and five times as high as non-users of mobility devices, and only about 7 percent have kitchen modifications (seven times as high as non-users of mobility devices).

Unmet need for home accessibility features is substantial (Figure 5). The most common unmet needs among wheelchair users are automatic or easy-to-open doors and elevators, lifts, or stair glides, at about 13 percent of wheelchair users. Among people with disabilities who do not use mobility devices, unmet need for these features is less than 1.6 percent.

Difficulties that people experience getting into or out of their homes and using their homes are also indicators of unmet needs. Fully 50 percent of people who use wheelchairs must use steps or stairs to get into their homes. Although this fraction is lower than the 68 percent of people with disabilities who do not use mobility devices, it is still very high and would seem to indicate a big problem for users of wheeled mobility

Figure 5. Home accessibility features among wheelchair users, present and needed, ages 18 and over



devices. Also, about half of users of wheeled mobility devices have difficulty entering or leaving their homes, which is often caused by steps and stairs in entryways, but can also be caused by narrow approaches and doorways, or steep or irregular pathways. The two measures are related, but not identical. Steps do not necessarily imply difficulty getting into one’s home. Over 90 percent of people who use wheelchairs have difficulty walking up 10 steps, but some may have no difficulty walking over a step or two. In fact, one-third of Wheeled mobility device users who have steps or stairs in their entryway report no difficulty getting into their homes. This may be because they are able to ambulate over the steps and stairs. It may be that Wheeled mobility device users may use other alternatives, such as leaving a scooter outside the home, while using other devices inside the home, such as a walker or manual chair. In fact, about 41 percent of scooter users also use a manual wheelchair. Even more striking is the observation that some 40 percent of wheelchair users use a walker, and 35 percent use a cane.

Getting around outside the home

About a third of users of wheeled mobility devices report they have accessibility problems getting around outside their homes. This is asked in the context that it is “because of a health problem or impairment,” a criterion which can suppress the question being endorsed by people who see access problems as having little to do with health problems or even impairments for that matter, and who see the problems as socially constructed.

About 26 percent of Wheeled mobility device users drive a vehicle at all. Of them, 31 percent have special equipment installed in their cars. The most common being hand controls (64 percent), followed by ramps or lifts (41 percent), power controls for windows, mirrors, seats, or steering (40 percent), a button to open doors (20 percent) or other equipment (36 percent). About 11 percent need equipment for their cars that they do not have.

Almost a third of Wheeled mobility device users do not live in areas with public transit services. Most Wheeled mobility device users who live in transit served areas do not use public transportation, whether buses, rapid transit, subways, or street cars: only 6.5 percent have done so in the past year. This rate is highest in central city areas at 8.5 percent.

About 80 percent of Wheeled mobility device users say that public transportation is difficult to use or get to, and two thirds say that it is very difficult. Forty percent say that they have wheelchair or scooter access problems in using public transit. It seems that more Wheeled mobility device users use paratransit than public transit. A quarter of Wheeled mobility device users have used paratransit in the past 6 months. During the week before the interview, 23 percent drove a car, and 64 percent rode as a passenger in a car. Only 3.6 percent rode an accessible bus and 3.7 percent rode an agency-provided van.

The dynamics of wheeled mobility device use

The survey asked about wheelchair use at the time the survey was being conducted. In Phase 1, users were asked if they expected to use wheeled mobility devices for 12 months and 81 of users thought they would. In Phase 2, people were asked if they used wheeled mobility devices in the past two weeks and in the past year. Only 60 percent of people who used a wheeled mobility devices in the past year did so in the past two weeks. This suggests that use of wheeled mobility devices is dynamic, with some people using wheeled mobility devices for a short while. This undoubtedly contributes to some of the observed low fractions of users with accessibility features, as some people use the devices for awhile, improve, and no longer need them. In that case, they are not very inclined to make or demand changes in their environments in order to make them more accessible.

Conclusions and recommendations

Once a severe mobility impairment is present, a variety of adaptations are possible. A person may choose which device(s) among canes, walkers, scooters, and wheelchairs they can and want to use. Affordability of wheeled mobility devices and financing issues are very important to this decision. Characteristics of the built environment further constrain device choices, so that if the home or community is not accessible to a wheelchair, the person may need to modify the home or perhaps rely on a less optimal device. Availability of human help also comes into play.

There is no doubt that the population of Wheeled mobility device users has grown immensely over the past 30 years, increasing by more than six-fold, at an average annual rate of 5.9 percent growth per year. This growth far exceeds the growth in the older population, and suggests that social and technological factors have played a prominent role. At that rate, by 2010, we would expect there to be 4.3 million users of wheeled mobility devices.

Refined predictions must await several questions that remain. Not all people with severe mobility limitations use wheeled mobility devices and there is no single measure of mobility limitation available from national surveys that can be used to accurately predict future demand for wheeled mobility devices. Functional mobility limitation has only recently begun to be measured in national surveys, and there is not a long enough time series to provide a foundation for projections. Furthermore, studies have not been done to evaluate which measures are the best set of predictors of wheeled mobility devices. There is evidence that people of younger and older ages do not think about these questions in the same way. Although older and younger groups of people may think about “walking” differently (called differential item functioning in the measurement field), there is the related but separable issue that the meaning and importance of walking changes with age. For example, younger people may use a wheelchair if they cannot walk long distances, so they can get around the community more easily and do more things. It is expected that older persons cut down on walking. They may use canes and walkers to go short distances, and may use transportation services to get around the community, rather than using a wheelchair to achieve the same goal.

There are differences in the significance of different measures of ambulation between nonelderly and elderly persons, and it is important to compare the two groups. Future changes might increase the popularity of wheeled mobility devices among the elderly, such as reductions in stigma associated with using wheeled mobility devices, continued increased longevity at the older ages, and further improvements in the built environment.

Additional analysis to identify the best set of predictors for use of wheeled mobility devices is needed. Furthermore, some studies have observed a decline in functional limitations at the older ages (Freedman and Martin, 1998) which may to some extent offset the impact of the aging population.

Some people with mobility impairments use mobility devices and some use human help. The research literature has begun to acknowledge that there is a choice to be made between use of mobility devices and human help (Verbrugge and Sevak, 2003). In the future, it can be anticipated that the availability of human help will decline, as boomers have fewer children available to help them than their predecessors. This may cause people to use wheeled mobility devices more readily.

A number of data issues emerge from this analysis. While the National Center for Health Statistics has periodically measured use of assistive devices, including wheeled mobility devices, there has been no measurement made since 1997 of particular devices used. The NHIS only asks about using any special equipment without further differentiation. The NHIS does ask about mobility limitations in the core survey, including inability to walk a quarter mile and walking up stairs and several other functional limitations (the severity of all being measured as some or a lot of difficulty or unable, assessed in the “naked” state) which can be helpful for making future projections as the data becomes available. In 2002, a number of questions were asked about barriers in the built environment and their impact on participation (see Appendix). The 2001 panel of the SIPP has fielded questions on wheeled mobility devices, although they do not distinguish between power and

manual wheelchairs. This data will add a few more recent time points to the trends described herein.

Yet, in the end, the collection of information about use of wheeled mobility devices in national statistics remains superficial and episodic. It should not remain so. The NHIS-D has shown that it is possible to ask useful questions about prevalence, trends, payment and financing, unmet need, and barriers and accommodations. The fact that powered and manual use is not distinguished is a problem that constrains information on the growing population of powered Wheeled mobility device users.

Often, AT and wheeled mobility devices are viewed as medical devices. In Phase 2 of the NHIS-D, mobility devices are included in a list of medical devices and implants (Phase 1 asked about sensory, communication, and mobility devices). In Phase 2, a question was asked about how much the individual or family paid for such devices in the past year, but it turns out that users of wheeled mobility devices are pretty significant users of medical devices, so much so that it is impossible to unravel how much was paid for their wheeled mobility devices versus other devices. This tendency to lump AT and wheeled mobility devices with medical devices and implants is generally not useful and underscores the superficiality with which AT and wheeled mobility devices are treated, particularly in health surveys. It must be mentally difficult for people to add up a quick total of how much they have paid for up to 15 devices in the past year. This approach is far too cavalier to get meaningful information and is a wasted opportunity.

Until there is a sponsor for the collection of improved data, or any at all, the NHIS-D will remain the last time there was any significant measurement of issues around use of wheeled mobility devices. This may go on for the foreseeable future, as there are no plans to undertake another NHIS-D.

I strongly recommend the development of a survey module on AT and wheeled mobility devices use. For reasons elaborated above, and for practical reasons, it may be a good strategy to be inclusive of all AT use rather than focusing on wheeled mobility devices alone. This module can build on the questions used in the NHIS-D, but can take them to a higher level, covering important issues that have yet to be addressed and doing a better job of those that have been covered in the past. The module should be cognitively tested with users of wheeled mobility devices and AT generally, and then field tested with a small sample and the reliability and validity of the items assessed. If the measures are good, they can be offered for inclusion in national surveys.

Questions should be asked about why people have made the choices they have made regarding mobility devices. If someone uses a walker, and could better use a wheelchair, that is important to know. It is useful for understanding the use of wheeled mobility devices to know about not only why a person has chosen a particular device but also about the other devices they may have considered but did not choose.

Finally, I believe there remains much to be done to improve measurement of the severity of mobility impairments. What distinguishes some from a lot of difficulty? This self-

rating appears to be valid, but that has not been demonstrated. The only really significant distinction from those who have difficulty are those who are not mobile by themselves without human help or assistive devices. Even here it is necessary to distinguish from being unable to walk because of balance, strength and endurance issues and the like, when the person can control the movement of the legs, from those who cannot move their legs well enough to walk a few paces. In my mind, the measures used in surveys are not well enough developed to distinguish those who *must* use wheeled mobility devices.

I think it is also worthwhile to understand how mobility expectations change with age. Distance and endurance expectations are very different between nonelderly and elderly people, yet the measures asked seem not to recognize these differences at all.

Despite these issues, the data strongly suggest that financial and access problems result in substantial unmet need for wheeled mobility devices and unmet need for accessibility features in homes and communities as of 1997. The urgency for updating this information as accessibility continues to improve post-ADA is critical. Therefore, I urge the research community and sponsors of research to take the necessary steps to ensure that the situation of people with severe mobility impairments, including their spatial and environmental requirements, will remain a priority for research and for national statistics.

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Appendix
Year 2002 National Health Interview Survey Questions

Disability and Secondary Conditions

>DISUSEQ<

DIS.010

The next questions are about special equipment and assistive devices. By this we mean things such as hearing aids, wheelchairs, scooters, canes, prostheses, special phones, or special computer devices. Please **DO NOT** include eyeglasses, or false teeth.

Do you **NOW** use any special equipment or assistive devices to aid you in your usual activities?

- (1) Yes
- (2) No
- (7) Don't know
- (9) Refused

>DISAID<

DIS.020

Do you know of any special equipment or assistive devices that you do not currently have, but would aid you in your usual activities?

- (1) Yes (DIS.030)
- (2) No (DS_INTRO)
- (7) Don't know(DS_INTRO)
- (9) Refused (DS_INTRO)

>DISEQDIF<

DIS.030

How often do you have difficulties because you do not have this special equipment or assistive devices? Would you say always, often, sometimes, rarely, or never?

- (1) Always
- (2) Often
- (3) Sometimes
- (4) Rarely
- (5) Never
- (7) Don't know
- (9) Refused

DS_INTRO

The next questions are about your surroundings at home, school, work, or the community, and possible barriers that might limit or prevent your activities. **FR: SHOW FLASHCARD D1** By barriers we mean things such as building design, lighting, sound, household or workplace equipment, crowds, sidewalks and curbs, transportation, attitudes of other people, and policies.

>DISHOME<

DIS.040

FR: SHOW FLASHCARD D1

Thinking of your **HOME SITUATION**, do problems with any of these things on the list **NOW** limit or prevent your participation in home activities or household responsibilities?

- (1) Yes (DIS.050)
- (2) No (DIS.070)
- (7) Don't know (DIS.070)
- (9) Refused (DIS.070)

>DIHM< Which ones? (Probe: Any others?)

DIS.050 **FR: SHOW FLASHCARD D1. MARK ALL THAT APPLY. ENTER (N)**

FOR NO MORE

- (1) Building design (stairs, bathrooms, narrow or heavy doors)
- (2) Lighting (too dim to read, signs not lit, too bright, too distracting)

- (3) Sound (background noise, inadequate sound system)
- (4) Household or workplace equipment hard to use
- (5) Crowds
- (6) Sidewalks and curbs
- (7) Transportation
- (8) Attitudes of other people
- (9) Policies (rental policies, eligibility for services, workplace rules)
- (10) Other barriers
- (77) Don't know
- (99) Refused

(goto DIS.060)

>DISHMOFT<

DIS.060 How often do these things limit or prevent your participation in home activities? Would you say always, often, sometimes, or rarely?

- (1) Always
- (2) Often
- (3) Sometimes
- (4) Rarely
- (7) Don't know
- (9) Refused

>DISSCH<

FR: SHOW FLASHCARD D1

DIS.070

Thinking of SCHOOL, UNIVERSITY, OR CONTINUING EDUCATION, do problems with any of these things on the list NOW limit or prevent you from getting training or going to school?

- (1) Yes (DIS.080)
- (2) No (DIS.100)
- (3) Do not attend school/training for other reasons (DIS.100)
- (7) Don't know (DIS.100)
- (9) Refused (DIS.100)

>DISC< Which ones? (Probe: Any others?)

DIS.080 **SHOW FLASHCARD D1. MARK ALL THAT APPLY. ENTER (N)**

FOR NO MORE

(1) Building design (stairs, bathrooms, narrow or heavy doors) (2) Lighting (too dim to read, signs not lit, too bright, too distracting)

- (3) Sound (background noise, inadequate sound system)
- (4) Household or workplace equipment hard to use
- (5) Crowds
- (6) Sidewalks and curbs
- (7) Transportation
- (8) Attitudes of other people
- (9) Policies (rental policies, eligibility for services, workplace rules)
- (10) Other barriers
- (77) Don't know
- (99) Refused

(goto DIS.090)

>DISCHOFT<

DIS.090 How often do these things limit or prevent you from getting training or going to school?
Would you say always, often, sometimes, or rarely?

- (1) Always
- (2) Often
- (3) Sometimes
- (4) Rarely
- (7) Don't know
- (9) Refused

>DISWRK< FR: SHOW FLASHCARD D1

DIS.100 Thinking of your WORK situation, do problems with any of these things on the list NOW limit the work you do or prevent you from working?

- (1) Yes (DIS.110)
- (2) No (DIS.130)
- (3) Do not work for other reasons (DIS.130)
- (7) Don't know (DIS.130)
- (9) Refused (DIS.130)

>DIWK<

DIS.110 Which ones? (Probe: Any others?)

SHOW FLASHCARD D1. MARK ALL THAT APPLY. ENTER (N) FOR NO MORE

- (1) Building design (stairs, bathrooms, narrow or heavy doors)
- (2) Lighting (too dim to read, signs not lit, too bright, too distracting)
- (3) Sound (background noise, inadequate sound system)
- (4) Household or workplace equipment hard to use
- (5) Crowds
- (6) Sidewalks and curbs
- (7) Transportation
- (8) Attitudes of other people
- (9) Policies (rental policies, eligibility for services, workplace rules)
- (10) Other barriers
- (77) Don't know
- (99) Refused

(goto DIS.120)

>DISWKOFT<

DIS.120 How often do these things limit or prevent you from working? Would you say always, often, sometimes, or rarely?

- (1) Always
- (2) Often
- (3) Sometimes
- (4) Rarely
- (7) Don't know
- (9) Refused

>DISCA< FR: SHOW FLASHCARD D1

DIS.130 Thinking of COMMUNITY ACTIVITIES such as getting together with friends or neighbors, going to church, temple or another place of worship, movies, or shopping, do problems with any of these things on the list NOW limit or prevent your participation in community activities?

- (1) Yes (DIS.140)
- (2) No (DIS.160)
- (3) Don't know(DIS.160)
- (4) Refused (DIS.160)

>DICA< Which ones? (Probe: Any others?)

DIS.140 **SHOW FLASHCARD D1. MARK ALL THAT APPLY. ENTER (N) FOR NO MORE**

- (1) Building design (stairs, bathrooms, narrow or heavy doors)
- (2) Lighting (too dim to read, signs not lit, too bright, too distracting)
- (3) Sound (background noise, inadequate sound system)
- (4) Household or workplace equipment hard to use
- (5) Crowds
- (6) Sidewalks and curbs
- (7) Transportation
- (8) Attitudes of other people
- (9) Policies (rental policies, eligibility for services, workplace rules)
- (10) Other barriers
- (77) Don't know
- (99) Refused

(goto DIS.150)

>DISCAOFT<

DIS.150 How often do these things limit or prevent your participation in community activities? Would you say always, often, sometimes, or rarely?

- (1) Always
- (2) Often
- (3) Sometimes
- (4) Rarely
- (7) Don't know
- (9) Refused

>DISHFAC<

DIS.160

The next questions are about access to health clubs, wellness programs or fitness facilities, such as the YMCA, community recreation programs, and employer fitness programs.

Do you NOW have ACCESS to a health club, wellness program or fitness facility that meets your needs, if you wanted to use one?

- (1) Yes (DIS.180)
- (2) No (DIS.170)
- (7) Don't know (DIS.180)
- (9) Refused (DIS.180)

>DISHFLIM< FR: SHOW FLASHCARD D2

DIS.170 Do any of these things on the list limit your access to a health club, wellness program, or fitness facility that meets your needs?

FR: MARK ALL THAT APPLY. ENTER (N) FOR NO MORE

- (0) None
- (1) Cost is too high for your budget
- (2) Lack of transportation
- (3) Lack of exercise equipment that meets your needs
- (4) Lack of an instructor to show you how to use the equipment
- (5) Accessibility to the building
- (6) Other
- (7) Don't know
- (9) Refused

Which ones? (Probe: Any others?)

FR: ENTER CODE FROM LIST ABOVE, ENTER "N" FOR NO MORE.

@1 @2 @3 @4 @5 @6 @7 @8 @9

>DISHFUSE<

DIS.180

DURING THE PAST 12 MONTHS, have you USED a health club, wellness program, or fitness facility at least 10 times?

- (1) Yes
- (2) No
- (7) Don't know {blind}
- (9) Refused {blind}

(goto Recontact Section)