



Blind Adults in America: Their Lives and Challenges

A Report by the National Center for Policy Research for Women & Families | February 2004

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Suggested Citation:
Diana M. Zuckerman, 2004
Blind Adults in America: Their Lives and Challenges
Washington, DC: National Center for Policy Research for Women & Families

This report was made possible by a grant from the Aid Association for the Blind of the District of Columbia. The report is based on a statistical analysis that was funded by Guide Dogs for the Blind and The Seeing Eye. The contents are solely the responsibility of the authors and do not represent the views of the funding organizations.

Blind Adults in America: Their Lives and Challenges was written by Diana M. Zuckerman, Ph.D. Special thanks to Kristine Witkowski, Ph.D, who analyzed the data; Mary Hager, Cathleen Witter, Madeleine Levin, Elinor Tucker, Dawn Dhavale and Nicole Hudak for their contributions to the report; neo design for designing the report; and the many advocates and people with vision impairment who provided support and suggestions for this project.

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Introduction

Approximately one million legally blind adults live in the United States. We know that many are older and increasing numbers live alone. However, there are many things we have not known about blind adults in our nation. Exactly where are they living? How many are living in poverty or near poverty? How is their health? What programs and services are they using, and are their needs being met? What are their daily lives like? Are there regional differences that we need to be aware of to improve policies for the adults who are blind?

Even the earliest civilizations recognized the unique needs of people who were blind. Blind men and women have made important contributions to society—as teachers, philosophers, and artists. It is therefore surprising how little research has been done to learn more about the lives of legally blind adults in contemporary American society. In fact, no nationally representative study had ever been done until very recently. This report is based on the first study conducted on a nationally representative sample of non-institutionalized legally blind adults in America.



:: The Study

In an effort to learn more about Americans with disabilities, the Centers for Disease Control and Prevention (CDC) decided that the National Health Interview Survey (NHIS) would be used to gather information about men, women, and children with disabilities living all across the country. They interviewed thousands of adults and children with disabilities in 1994 and 1995, including 779 legally blind adults representing 993,766 non-institutionalized adults ages 18 and older nationwide, and 52 children representing 65,296 non-institutionalized legally blind children ages 5 to 17 nationwide. The federal government, however, never used the data to provide information to advocates or policy makers about the daily lives of legally blind adults and children.

The National Center for Policy Research (CPR) for Women & Families used the NHIS data to conduct the first comprehensive statistical analysis of data on blind adults. With the support of the Aid Association for the Blind of the District of Columbia, we have summarized the information into this report. Some of the findings support assumptions that have been made about blind adults, while other findings highlight previously unrecognized needs of this very important group of Americans.

:: Why Study Adults Who Are Blind?

The policy implications of blindness in the United States are staggering. Americans are living longer than ever before. As the population ages, the number of blind adults increases. Consequently, the number of blind adults who do not have others to care for them also increases. While most blind adults are married or living with relatives, as they age they may outlive their spouses or relatives. This is of particular concern for women, who are more likely to outlive their spouses and live alone. The more information we have about blind adults, the better we can understand what policies and services are needed to help these men and women continue to live independent, satisfying, and productive lives.

Some Highlights

How old are they?

It's no surprise that most blind adults are older than the general population. Our study shows that their average age is 62, and one out of every three is over the age of 75.

Who do they live with?

One in five blind men lives alone, but that decreases after age 75. In contrast, although few young blind women live alone, blind women are more likely to live alone as they get older, and the majority live alone after age 75. Older blind white women are much more likely to live alone than their African American and Hispanic counterparts.

How did they become blind?

The majority of blind adults had sight when they were young and became blind due to illness. However, a substantial number of men became blind due to accidents.

Do they live in poverty?

Poverty is a fact of life for many blind adults, especially older women. Few blind adults receive welfare. Most blind men in poverty receive food stamps, but most blind women in poverty do not.

What services do they use?

Almost none of the blind men or women reported receiving vocational rehabilitation, occupational therapy, or any other services available to help them cope with losing their vision.

Olivia N. was born 16 weeks prematurely, which led to blindness when she was three months old. Now an attractive, friendly, and accomplished 22-year-old, Olivia has battled health problems all her life. She is a junior in college, and has managed to make the Dean's list and retain a scholarship in spite of the interruptions to her education caused by her medical problems. She is fortunate to have well-educated parents who have encouraged her every step of the way and have the resources to provide the best medical care. Olivia remains upbeat and is determined to pursue her dream of becoming a medical social worker.

What about blind children?

It is unfortunate that the NHIS study included only 52 blind children between 5–17 and thus provided limited information about children. However, since this was a representative sample, we can use the data to provide useful comparisons between adults and children. For example, blindness is often only one of several serious disabilities afflicting children who are blind, probably when blindness is a result of premature birth or brain damage. More than 40 percent of the children in the study had learning disabilities, for example, and 20 percent were considered mentally retarded. These disabilities were rare in blind adults. Compared to adults, blind children are more likely to be male and less likely to be white. Almost half of the blind children live in the South, compared to only 35 percent of the adults. This raises important questions about potential causes of blindness, such as access to prenatal care—questions that can't be answered by this study. Because the sample of blind children in the study was small, this report will only discuss research findings on adults ages 18 and older.

Why do this report now?

Blindness is often a result of diseases associated with aging. The size of the blind population is increasing. As baby boomers age and Americans live longer, the number of blind adults, the challenges that confront them, and the implications for our society will increase in magnitude. If we as a nation are to meet the needs of this growing population, our policy makers must have objective information about those needs. The findings from this first-of-its-kind analysis highlight several issues to help our leaders craft effective policies.

Findings



This report is based on adults who reported that they were legally blind or whose family member reported that they were legally blind, in response to a direct question asking “Are you (or is he or she) legally blind?” Legal blindness is defined as corrected eyesight no better than 20/200 for either eye or a restricted field of vision less than 20 degrees wide.

The survey results indicate that there are 993,766 legally blind, non-institutionalized adults ages 18 and older in the United States. They vary tremendously on virtually every measure, from race and ethnicity, education, work history, family income, medical status, mental health, and the ability to perform the tasks of daily living.

Demographic, Household, Health and Economic Characteristics

Basic Information

- More than three-quarters (79 percent) are white, 12 percent are black, and 6 percent are Hispanic*
- Almost half (49 percent) are married
- The average education is 11.4 years
- The proportion of blind adults who are white is greatest for those over age 75
- Approximately half of blind men over 65 are veterans, but less than one-third of younger blind men are veterans

Male and Female

- Half of the blind adults are male and half are female
- Men comprise 58 percent of those between the ages of 18–44
- Women comprise 61 percent of those over the age of 75

Marriage and Household

- Blind men are more likely to be married than blind women, regardless of age
- As blind men age, they are more likely to be living with a spouse
- As blind women age, they are more likely to be living alone or with a relative

Location

- Most blind adults (78 percent) live in an urban area
- More blind adults (35 percent) live in the South than in any other geographic area
- Rural and urban blind adults do not differ in terms of age or sex

Poverty

- Nearly one in five (19 percent) lives in poverty
- Only 19 percent are currently employed
- All of the adults in the survey have worked in their lifetimes, either for pay or as volunteers

Regional Differences

More than one-third of adults who are blind live in the South. The rest are almost evenly distributed in the other three regions: the Northeast, Midwest and West. There are interesting regional differences that influence how these blind adults live. For example, blind men outnumber blind women in the South, while the pattern is reversed in the other three regions. Blind adults are older in the Northwest, more likely to be married in the South, less educated in the South, and more educated in the West. Blind adults in the Northeast (89 percent) and West (86 percent) are more likely to live in an urban area than in the South (70 percent) and Midwest (71 percent).

* This government survey categorizes race and ethnicity as Hispanic, non-Hispanic white, non-Hispanic black, Asian or Pacific Islander, and other.

Causes of Blindness and Current Health Status

More than four out of five blind adults had impaired vision for more than 5 years. Blindness was caused by disease for nearly half of the population. The most common reported causes are diseases of the retina (26 percent), diabetes (7 percent), glaucoma (7 percent), and cataracts (4 percent). Accidents accounted for 15 percent of blindness in adults and 8 percent in children. At all ages, but especially among those 45 or older, men have a higher percentage of blindness caused by accidents.

Everyone in the survey was asked to rank his or her health on a five-point scale. Only 12 percent rated their health as “excellent,” 15 percent rated their health as “very good,” 27 percent rated their health as “good,” 25 percent rated their health as “fair,” and 20 percent rated their health as “poor.”

Almost all of them—94 percent—reported at least one health problem. They reported an average of 3.3 health conditions each, in addition to their blindness.

Many blind adults also have other disabilities. Almost one in five have trouble hearing, even with a hearing aid. An equal number report problems with balance. Very few report serious learning or neurological disabilities: only 5 percent had been diagnosed as having a learning disability, 2 percent are mentally retarded, and 1 percent were born with cerebral palsy.

When asked about emotional and mental health problems, more than one in four (29 percent) reported one or more emotional or mental problems; in addition, 29 percent of those individuals felt that their emotional or mental difficulties seriously impaired their lives. Emotional problems were mentioned by 17 percent of blind adults, who said they were frequently depressed or anxious; 13 percent were frequently confused, disoriented, or forgetful; 9 percent had trouble coping with daily stresses; and 7 percent said they had trouble concentrating long enough to complete tasks. Only 6 percent reported one or more serious mental health conditions; half of those were major depression.

∴ 75-year-old Ben has lost most of his vision due to macular degeneration. He was divorced many years ago, and his daughter helped him until she died in a car accident last year. He relies on his home care worker, Karina, who comes twice a week to do housecleaning, grocery shopping, and other tasks. Ben cannot afford to pay for full time care, and he doesn't want to move to an assisted living facility, insisting on maintaining his independence. He rarely leaves his apartment, finds it difficult to access information that could help him, and is increasingly isolated and vulnerable to injury and depression.

Family Income and Education

Annual family income ranged from below \$5,000 to more than \$50,000, with almost equal distribution in all income categories included in the survey. No significant differences in annual family income were linked to age or sex, although the number of women living in poverty increases after the age of 44.

Blind adults are less well educated than the general population. The average number of years of education for blind adults is 11.4. Many (40 percent) did not obtain a high school diploma, 32 percent are high school graduates, 16 percent have some college education, and 12 percent are college graduates. In contrast, only 25 percent of the general population of adults does not have a high school education; 18 percent have a college or graduate degree. Age influences the level of education: Younger blind adults tend to have more education. The educational attainment of men and women does not differ substantially. The lower educational attainment of the group as a whole is probably related to age as well as blindness, since individuals born earlier in the 20th century are less likely to have completed high school.

There were important regional differences in poverty among blind adults. Almost one in four (24 percent) of blind adults in the South lives in poverty, compared with fewer than one in five in the Northeast (18 percent), Midwest (19 percent), and West (13 percent). Similarly, 21 percent of legally blind adults in the West have an annual family income of \$50,000 or more, and 20 percent are employed. Comparable statistics for the Northeast were 11 percent with incomes over \$50,000 and 14 percent employed, for the Midwest 10 percent with incomes over \$50,000 and 24 percent employed, and for the South 13 percent with incomes over \$50,000 and 18 percent employed.

..... Stephanie O. was born with congenital glaucoma. Her vision has been impaired since infancy, but she was able to read print and did well in school. Her vision slowly declined, and now at the age of 56 she can't read print at all and uses a white cane. She is a civil rights attorney who has worked for the federal government and at advocacy organizations in New York, Indiana, and Washington, DC. She says her profession seems shocking to many. "So many people, including health and rehab professionals, don't have any idea of what legally blind people can and can't do."

Work and Other Daily Activities

What do blind adults say about their daily lives? Although only 19 percent are currently employed (most do not work due to age or disabilities), only one in five said they were unable to perform personal care activities. However, almost half (46 percent) reported limited ability to perform personal care activities.

Despite their age, disabilities, and health problems, most blind adults are able to perform most of the “activities of daily living” listed in the survey (bathing, dressing, eating, getting in/out of beds/chairs, using the toilet, and getting around inside the home). Only one in four (24 percent) said they have difficulty performing any of these activities. The ability to perform personal care activities decreases with age. Two-thirds of blind men and approximately half of blind women between ages 18–44 reported no limitations at all, but by the time they were 75 or older, one-quarter of the blind men and one-third of the blind women reported being unable to perform personal care activities at all.

Although almost all blind adults can use the telephone and many are able to shop, prepare meals, manage money, and do housework, more than half (52 percent) reported problems with at least one of these “instrumental” activities of daily living. The percentage of blind adults reporting one or more difficulty with these activities increases with age from one-quarter of men and one-third of women between 18–44 years of age to 62 percent of men and 75 percent of women who are at least 75 years old or older.

A third category of daily activities includes “functional” activities such as walking, lifting, standing, bending, reaching, holding a pen, and walking up steps. Approximately 30 to 40 percent of all blind adults experience difficulties in each of these five functional activities: walking, lifting, standing, bending, and walking up steps. These are probably related to aging. Fewer than 15 percent had any difficulty either reaching, using fingers, or holding a pen or pencil. Overall, blind adults average two functional difficulties each, but 47 percent have no functional difficulties at all. By the age of 75 or older, however, 60 percent of blind men and 79 percent of blind women reported at least one functional difficulty.

Most of these limitations on daily activities seem to be related to aging, but some may be a result of not learning how to do activities as a blind person that the individual knew how to do before he or she became blind.

The men and women who relied on others for assistance usually relied on relatives. However, almost half of those who received help with activities of daily living, such as bathing, paid for the service. The much larger number of adults who receive help with instrumental activities (such as shopping) or functional activities (such as walking) were much less likely to pay for help.

Programs and Services

How many services and types of equipment designed for the visually impaired are used by legally blind adults? Apparently, not many. Only one in four (28 percent) uses visual “equipment.” The most common choices are white canes (12 percent), telescopic lenses (9 percent), and Braille (5 percent). Less than 1 percent use a guide dog. Use of adapted computer technology was rare, but is probably more common today.

Despite their age, only one-third (34 percent) of blind adults use mobility equipment. Of those, almost three-quarters (72 percent) use a cane (but not a white cane), crutches, a walker, prescribed shoes, or a brace.

Very few blind adults report receiving therapy of any kind. For instance, only 13 percent have ever received vocational rehabilitation. Only 11 percent received physical therapy in the past year. Even fewer received occupational therapy in the past year (3 percent). Seven percent use prescription drugs for mental health treatment.

Given that most blind adults became blind later in life, they might benefit greatly from these types of services. It is important to determine why they are not getting them and how services could be made more readily available to them through various public and private agencies. For example, 18 percent of legally blind adults are veterans, who could possibly have access to services through the Department of Veterans Affairs (VA).

When Dudley’s sight began to deteriorate due to macular degeneration, retinal scarring, and the effects of laser treatments, his wife took immediate action. She convinced him to take classes at the Orientation Center for the Blind in a nearby town. “I spent six months there learning to take care of myself... I learned all about using a cane and traveling independently.” He later decided a guide dog would be even more helpful, and Burton, a friendly Yellow Lab, became his constant companion. Dudley became a volunteer peer counselor at the Orientation Center. “It’s important for me to know that I’m doing something to help someone else,” he explains.

The remainder of this report focuses specifically on two groups that require additional policy attention: blind adults living in poverty, and blind adults living alone.

Blind Adults Living in Poverty

Almost one in five (19 percent) of legally blind adults lives in poverty, but only three percent reported that they are on welfare. Five percent stated that they receive food stamps.

Poverty is a problem for approximately one in five blind women, regardless of their age. Poverty is less common for older men. While almost equal numbers of legally blind men and women under 65 are living in poverty (21 percent and 24 percent respectively), the gender gap widens after the age of 65, with only 8 percent of men living in poverty and 21 percent of women living in poverty.

Why? Do blind men somehow improve their financial situation as they age? A more likely explanation is that many older blind men were not blind during their young adult years; they may be living more securely than young blind men or blind women due to pensions and Social Security.

Pensions also explain the differences between women and men. Between the ages of 65 and 74, 30 percent of blind women and just over one-third of blind men receive pensions. But after age 75, the gender gap is more dramatic: almost half of the men receive a pension, while the percentage for women remains steady at 30 percent.

This gender difference is not unique to blind adults. For the general population, there is also a gender gap for poverty, with 12 percent of men living in poverty compared to almost 16 percent of women.

Poverty is also linked to race. For women between the ages of 17 and 64 who are living in poverty, about half (51 percent) are white, whereas among women in that same age group who are living above the poverty level, three-quarters (76 percent) are white. Men show a similar pattern. In the same age group, 61 percent of those living in poverty are white while 80 percent of those not living in poverty are white. The census figures show that nearly half of the general population living in poverty is white, while approximately two-thirds of those not living in poverty are white.

As with the general population, marital status and education are linked to poverty. For blind men and women, individuals who are living in poverty are less likely to have graduated from high school. Blind men and women living in poverty are less likely to be currently married. They are also more likely to live alone than those who are not living in poverty.

Blind adults who work are less likely to be poor. Only 16 percent of blind women who are living in poverty are employed, compared to 39 percent of blind women living above the poverty line. Likewise, 18 percent of blind men below the poverty line are employed, compared to 40 percent of blind men living above the poverty line.

Almost half of blind adults receive Social Security or disability benefits, although many of them are below the poverty line. Other government assistance programs are not widely used, especially by blind women: Blind men in poverty are more likely to receive food stamps than blind women in poverty (65 percent vs. 37 percent). Blind women in poverty are more likely to receive welfare benefits than men (24 percent vs. 12 percent), which is not surprising since welfare available at the time of the study was designed primarily for mothers of young children. Even so, many blind adults living in poverty did not benefit from welfare or food stamps, even though these data were collected prior to the implementation of welfare reform in 1997. It is not possible to tell from this study whether welfare reform has changed these findings.

Blind adults who are poor are more likely to be living in rural areas than those who are not poor (30 percent compared to 20 percent). About one-half of both men and women living in poverty live in the South.

Blind Adults Ages 17–64	Northeast	Midwest	South	West
Women in poverty	8%	19%	52%	19%
Women above the poverty line	19%	26%	31%	26%
Men in poverty	18%	17%	50%	32%
Men above the poverty line	19%	26%	14%	23%

..... Tobi H. is legally blind and uses a wheelchair. She depends on Social Security for her income, a meager \$602 a month. She is currently ill, and her medications cost \$4,000/month. Although she was working fewer than 10 hours a week, that income plus her Social Security check made Tobi ineligible for Medicaid. But as a part-time employee, she had no access to health insurance through work. With the help of her Social Security caseworker and state legislators, she applied for the Home Based Community Services program, which will allow her to get back on Medicaid ... "I don't know how anyone works their way through this system without help," says Tobi.

In summary, blind adults most likely to live in poverty are women residing in the South who are non-white, unemployed, less educated, and have limited social networks.

Living in poverty is linked to physical and mental problems for blind adults, although it is not clear whether poverty exacerbates or is caused by these other disabilities. Blind men living in poverty are more likely to report difficulties hearing conversation, even with a hearing aid (19 percent), compared to those not living in poverty (7 percent). For blind women, the same holds true: 11 percent of those living in poverty reported the same problem, as opposed to 2 percent not living in poverty. Blind women and men living in poverty were more likely to have problems with balance (35 percent and 21 percent, respectively), compared to those not living in poverty (11 percent and 11 percent).

When rating their overall health, blind women and men in poverty were much more likely to rate their health as fair or poor than their more financially secure counterparts. Blind women and men above the poverty line were more likely to report their health as “excellent,” “very good” or “good” than blind women and men living below the poverty line (59 percent and 70 percent respectively, compared to 43 percent and 48 percent).

Blind women and men in poverty report higher percentages of emotional and mental problems such as depression, anxiety, trouble with friendships, trouble in social settings, concentration difficulties, stress coping difficulties, confusion, disorientation, and phobias than do blind women and men not living in poverty. In addition, blind adults living in poverty are more likely to report one or more emotional/mental problem compared to blind adults who do not live in poverty: 52 percent and 47 percent for women and men living in poverty, compared to 29 percent and 22 percent for women and men living above the poverty line.

Blind Adults Living Alone

One out of every four (26 percent) blind adults lives alone, but the patterns are different for men and women of different ages. Blind women are more likely to live alone as they age. Only 7 percent of blind women between the ages of 18–44 live alone, but the percentage more than doubles to 16 percent between the ages of 45–64. In the 65–74 age group, more than one-third live alone. More than half (52 percent) of blind women 75 and older live alone. In contrast, approximately 20 percent of blind men live alone at all ages, falling to 16 percent for those over 75.

Race and ethnicity affect this pattern. Between the ages of 17–64, 62 percent of blind women living alone are white, 36 percent are black, and 2 percent are Hispanic. However, among those 65 and older, 91 percent are white, 5 percent black, 2 percent Hispanic and 2 percent other. In contrast, just as there are no age differences, there is no racial difference in the percentage of blind men living alone.

The vast majority (94 percent) of older women who live alone are divorced, widowed, or separated, compared with 70 percent of younger women. The remainder (30 percent) of the younger women have never married, compared to 5 percent of the older women. Approximately two-thirds of the younger and older men living alone are divorced, widowed, or separated, and the rest never married.

Blind men and women living alone have similar educational levels, except that younger women are more likely to have attended (but not graduated from) college than their male peers. Older men are more likely to have attended (but not graduated from) high school than their female peers.

Blind adults who live alone are more likely to live in poverty than the general population. Approximately one-third of blind men ages 18–64 and blind women and men ages 65 and older live in poverty, but almost half (48 percent) of blind women ages 18–64 live in poverty.

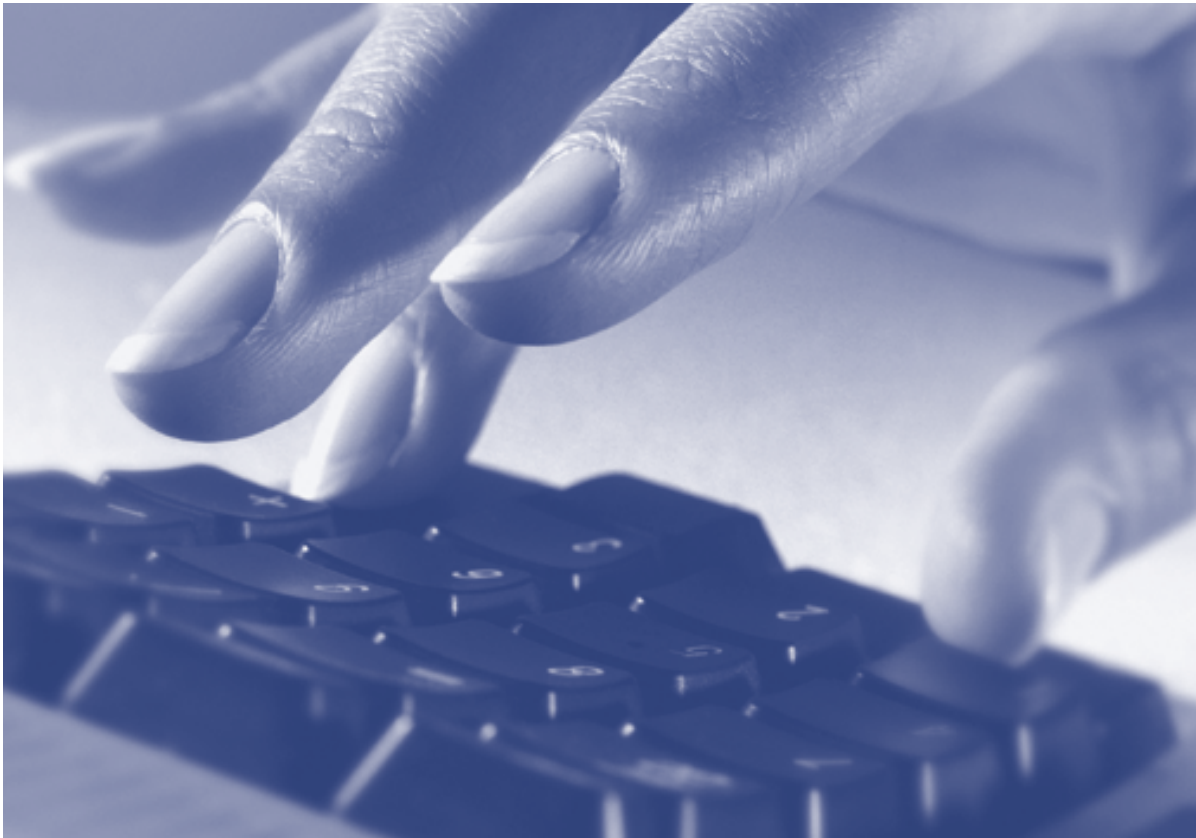
Comparable proportions of blind women and men under the age of 65 living alone receive Social Security, as do blind women and men over the age of 65. Only 32 percent of blind women over 65 and 15 percent of blind men over 65 receive pensions based on a lifetime of employment, which is considerably more than the younger women and men.

Blind women and younger men living alone almost never report receiving welfare. Only 8 percent of older men living alone receive welfare. Blind men are much more likely to receive food stamps than blind women: 42 percent of younger blind men received food stamps compared to none of the younger blind women, and 23 percent of older blind men received food stamps, compared to 13 percent of the older blind women. This disparity raises an important question that deserves attention: Since so many of them are poor, why do legally blind women between the ages of 18 and 64 who live alone not receive food stamps?

The income distribution of blind women living alone is different from blind men living alone. While younger blind women are more likely to live in poverty than any other group, there are also more younger blind women at the highest income levels. Their income distribution does not follow the same pattern as the other groups: approximately half the older blind women and younger and older blind men have incomes between the poverty line and \$25,000, whereas almost half the younger blind women are living below the poverty line but only 20 percent report incomes between the poverty line and \$25,000. At the other extreme, 10 percent of younger blind women living alone have family incomes of \$50,000 or more, compared to 1 percent of older blind women, no younger blind men, and 4 percent of older blind men. It appears that blind women living alone are more likely to be very poor or relatively affluent, with fewer between those extremes.

There are major geographic differences among blind adults living alone. Younger women (17–64) living alone primarily reside in the Midwest (41 percent), with about 1 in 4 living in the South (26 percent) and West (24 percent), and only 8 percent in the Northeast. The older women living alone are more evenly distributed geographically. About one in five lives in the South (21 percent), and about one in four lives either in the West (23 percent), Midwest (28 percent), or Northeast (28 percent).

Younger men living alone are most likely to live in the South (33 percent) or Midwest (29 percent), and less likely to live in the West (23 percent) and Northeast (15 percent). Approximately one in three (34 percent) of the older men lives in the South (34 percent), but one in four lives in the Northeast (26 percent) and one in five lives either in the Midwest (19 percent) or West (21 percent). The women living alone seem to be most concentrated in the Midwest and men living alone seem to be concentrated in the South.



❑ POLICY ISSUES

The major policy implications of these findings are as follows:

- Most blind adults have work experience and many below the age of 65 are healthy and well-functioning. Most are not currently employed, however. Regardless of age, sex, education, and income, few blind adults receive the kinds of services that could presumably help them succeed in the work force and remain independent and productive, such as vocational rehabilitation, occupational therapy, or visual equipment.
- Almost half of blind adults receive Social Security or disability benefits, but even they are more likely to live below the poverty line than other adults. Very few blind adults receive welfare or food stamps. Since welfare is designed for parents of young children, most blind adults do not qualify. The fact that men are more likely to receive food stamps than women and that adults living alone are least likely to receive benefits suggests that many blind adults may find the application process for receiving food stamps or other benefits too difficult. Assistance with the process or modification of it for blind adults could help them receive the benefits that they are entitled to.
- Most blind adults were not born blind and became blind as a result of diseases, not accidents. Data on causes are limited in this study, but prevention efforts that include diabetes, cataracts, and glaucoma could reduce blindness in a substantial number of Americans.
- As baby boomers age and longevity increases, the federal government needs to consider how to help blind adults who want to continue to live independently, but who have more health problems and disabilities as they age. Assistance may be especially necessary for blind women, most of whom live alone as they age, and many of whom live in poverty. Most blind women over 65 who are living alone are white.
- Approximately half of the blind men over the age of 65 are veterans, but less than one-third of those under 65 are veterans. The VA could potentially provide important assistance for many but not most blind men.
- Blind adults tend to live in urban areas and one-third live in the South. More than half the blind adults living in poverty live in the South. State and federal policies need to consider these geographic trends and do more to prevent blindness and provide services for those who need them.

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