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The New Jersey Capacity Building for Health and Disability Project

Sabrina Chase, Ph.D.
Sandra Howell-White, Ph.D.
Sarah Avery, Ph.D.

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EXECUTIVE SUMMARY

Introduction

The *New Jersey Capacity Building for Health and Disability Project* was commissioned by the Department of Human Services (DHS): Division of Disability Services (DDS), with financial support from the Centers for Disease Control and Prevention (CDC), US Department of Health and Human Services. For this project, the Rutgers Center for State Health Policy (CSHP) conducted a series of eight focus groups that included women and men living with a wide range of physical and cognitive constraints and surveyed 295 people from a number of disability communities across the state of New Jersey.

Focus Groups

Both telephone and in-person focus groups were convened and supplementary interviews were conducted. Focus groups included: Women living with low Vision or Blindness; Men living with low vision or blindness; Women 45 and older living with physical disabilities; Women 44 and younger living with physical disabilities; Men 45 and older living with physical disabilities; Men 44 and younger living with physical disabilities; Men and women living with cognitive disabilities; and Individuals identifying as late-deafened or as hard of hearing.

Across All Focus Groups

Major trends across all focus groups included:

- Difficulty finding and keeping doctors who were knowledgeable about their disabilities
- Insensitivity on the part of doctors, other professional healthcare providers, and intake staff (i.e., the perception of being treated as less than fully intelligent, capable adults)
- Inaccessibility of doctor's offices
- Transportation
- Problems with insurance of all kinds (private, Medicare, and Medicaid), especially inadequate coverage for assistive devices and difficulty accessing specialty care
- Lack of insurance coverage for preventive treatment and health promotion
- Difficulty finding and retaining skilled personal aides and assistants

- Difficulty maintaining healthy eating habits and exercise habits

Women's Focus Groups

The specific concerns articulated by women across various disability groups were:

- Gender bias among medical professionals
- Lack of STD testing and information
- Uneven access to fully accessible exam tables and mammogram machines

Men's Focus Groups

The specific concerns articulated by men across various disability groups were:

- The need for physical exercise to maintain health (especially cardiovascular health and mobility) and prevent the development of secondary conditions
- Lack of access or insufficient access to fitness and outdoor sports
- Day-to-day maintenance of mental health

State-Wide Survey

In total, 715 surveys were mailed by participating agencies to people living in the community with a response rate of 41.1% (N=295). Overall findings included:

- More than half of respondents reported that they never (32.5%) or rarely (25.2%) had problems getting health care services. Almost one in ten, however, reported that they *always* had problems
- Most perceived that their health care providers were uncomfortable with their disability (78.2%)
- About one-quarter said they avoided appointments because of their experience with providers (24.1%)
- One-fifth reported that providers lacked knowledge about their disability (20.6%)
- More than half rated their health as good (36.6%) or very good (24.7%). Less than five percent (4.5%) rated their health as poor
- Almost two thirds (59.6%) of our survey respondents reported that preserving or maximizing mobility was a serious concern for them

Key Recommendations

We recommend that several key health issues commonly mentioned across all focus groups be addressed. These recommendations include:

- Educating doctors, other professional healthcare providers, and intake staff regarding disability and gender bias issues
- Addressing inadequate coverage for assistive devices, health promotion and prevention, and difficulty accessing specialty care
- Developing ways to assist individuals to find doctors who are knowledgeable about disabilities and encourage doctors to be more open to working with these individuals
- Expanding ways to improve and maintain positive mental health, especially for men
- Encouraging and educating disability-diagnosing physicians (especially audiologists and low vision specialists) to refer their patients to disability support groups and retraining services
- Providing additional support for maintaining healthy eating and physical exercise habits in order to prevent the development of secondary conditions

Additionally, as a number of the problems faced by individuals with disabilities concerned their interactions with various care providers (physicians, medical staff, service providers, and fitness professionals), it may be worthwhile to initiate discussions or interviews with these individuals in order to better understand their perspectives and discover what could be done to make their interactions less challenging.

The New Jersey Capacity Building for Health and Disability Project

Sabrina Chase, Ph.D; Sandra Howell-White, Ph.D; Sarah Avery, Ph.D

Overview

The Department of Human Services (DHS): Division of Disability Services (DDS), with financial support from the Centers for Disease Control and Prevention (CDC), US Department of Health and Human Services, contracted with the Rutgers Center for State Health Policy to conduct the *New Jersey Capacity Building for Health and Disability Project*. Through this research, DDS sought to learn more about the health promotion and illness prevention activities of persons living with disabilities, understand their health care experiences, and define those ways in which the health care system could better serve their needs. To this end, the Rutgers Center for State Health Policy (CSHP) surveyed 295 people from a wide range of disability communities across the state of New Jersey and conducted a series of eight focus groups that included women and men living with a wide range of physical and cognitive constraints.

Initially, the project focused specifically on the health of women living with disabilities; the initial research plan called for a series of four focus groups including only women but representing individuals grappling with a range of disability types. These groups were selected to provide a deeper understanding of participants' health promotion and illness prevention activities. They included: 1) a mixed group of women over the age of 45; 2) a mixed group of women between the ages of 18 and 45; 3) a group of women living with cognitive impairments; and 4) a group of women living with sensory impairments. We established these four categories in order to address issues such as sexual health, pregnancy prevention and childbearing, special needs related to the aging process, and the role of caregivers and proxies for persons living with cognitive impairments.

In order to recruit women for these focus groups, we planned to work with the DDS and the collaborating agencies identified in the original CDC grant application to develop lists of potential participants. To ensure broad representation from across the state, we designed a short screening instrument emphasizing demographic and basic service use information that would allow us to invite women to the appropriate focus groups. However, in discussions with both DDS and the collaborating agencies, it became clear that there was a strong interest in collecting a wider range of data from a substantially larger group of New Jersey citizens living with disabilities. Because of this interest, we expanded the screening tool into a more detailed questionnaire to survey a larger statewide sample. This change also allowed us to expand the research project in order to include separate focus groups with men.

Research Methods

Focus Group Methods

Upon expanding the project, we modified our initial focus group categories and added in supplemental interviews in order to better understand the specific needs of persons living with particular types of impairments. For example, we initially planned to convene one exclusively male and one exclusively female focus group for persons living with sensory impairments, but we ultimately separated these two groups into separate sub-categories as follows: 1) women living with blindness or low vision; 2) men living with blindness or low vision; and 3) women and men identifying as late-deafened or hard of hearing. [1]

We used telephone conferencing to conduct most of the focus groups because the majority of individuals living with disabilities report moderate to severe transportation difficulties. We conducted in-person focus groups with those living with cognitive and hearing impairments. All supplemental interviews were conducted in-person. All focus group sessions and interviews were recorded on CD. CDs were reviewed and summarized. These summaries were combined with our focus group notes. The material was then reviewed for key themes. These themes are delineated in the focus group results section of this report. Table 1 presents a summary of the focus groups and interviews.

Table 1: Overview of Focus Groups

Focus Group Description	Type	Participants
Women Living with Low Vision or Blindness	Telephone	8 women
Men Living with Low Vision or Blindness	Telephone	7 men
Women 45 and Older Living with Physical Disabilities	Telephone	8 women
Men and Women Living with Cognitive Disabilities[a]	In-Person	15 women[b] and 14 men
Women 44 and Younger Living with Physical Disabilities	Telephone	7 women[b]
Men 45 and Older Living with Physical Disabilities	Telephone	5 men
Men 44 and Younger Living with Physical Disabilities	Telephone	5 men
Individuals Identifying as Late-Deafened or as Hard of Hearing	In-Person	12 women

[a] Included men and women; conducted following a support group meeting.

[b] Includes supplemental interviews conducted with 2 women

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[1] Although a group of men were invited to participate in this in-person focus group, none attended.

State-wide Survey Methods

While working with DDS and our collaborating agencies, we designed an 8 page mail survey. This length was considered optimal by both DDS and the collaborating agencies in terms of balancing the breadth of information gathered with the time and effort required to respond. The survey was designed to capture information about each participant's:

- Living situation
- Experience with health care providers
- Health insurance status
- Dietary and exercise activities
- Alcohol and tobacco use
- Personal characteristics

As there are no centralized lists of persons with disabilities, we worked with the collaborating agencies to develop a sampling strategy. In the absence of reliable population estimates or sample frameworks, we asked each agency to assemble a list of 50 persons (small agencies were asked to assemble a 30-person list). Due to concerns over confidentiality and HIPAA[2], it was determined that participating agencies would mail out pre-packaged survey packets utilizing their own individual lists. While this method did not ensure the random selection of agency clients, CSHP did explain the need to randomly select potential participants to all participating agencies and we emphasized the importance of avoiding a selection bias favoring active clients. The survey packets were assembled by Schulman, Rouca, Bucuvalas, Inc.(SRBI). SRBI, Inc. is a survey research firm located in New Jersey. This firm was subcontracted to print surveys, mail survey packets, and create the database from the returned surveys. The packets included both the survey itself and a cover letter introducing the packet and explaining the process. Packets also included a pre-addressed, stamped return envelope. Surveys were not marked with unique identifiers; thus, we were unable to track non-respondents so a second mailing to all potential respondents was sent to ensure an adequate response rate. The second survey mailing included a note instructing those who had completed the first survey to disregard the second survey mailing. With a total of 715 packets mailed and 295 completed and returned, the response rate was 41.1%.

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[2] The Health Insurance Portability & Accountability Act (HIPAA) was recently enacted to ensure confidentiality of patients' health information.

Results

Focus Group Trends

This section offers a summary of major trends emerging across several focus group categories (all focus groups, all women's groups, all men's groups, all sensory impairment groups).

Across All Focus Groups

Participants across *all* focus groups and interviews reported the following concerns:

- Difficulty finding and keeping doctors who were knowledgeable about their disabilities
- Insensitivity on the part of doctors, other professional healthcare providers, and intake staff (i.e., the perception of being treated as less than fully intelligent, capable adults)
- Inaccessibility of doctors offices
- Transportation
- Problems with insurance of all kinds (private, Medicare, and Medicaid), especially inadequate coverage for assistive devices and difficulty accessing specialty care
- Difficulty finding and retaining skilled personal aides and assistants
- Lack of insurance coverage for preventive treatment and health promotion
- Difficulty maintaining healthy eating habits and exercise habits without additional support (nutritional advice; personal trainers knowledgeable about disabilities and personal assistants)

Women's Focus Groups

The specific concerns articulated by women across various disability groups were:

- Gender bias among medical professionals
- Lack of STD testing and information
- Uneven access to fully accessible exam tables and mammogram machines

Men's Focus Groups

The specific concerns articulated by men across various disability groups were:

- The need for physical exercise to maintain health (especially cardiovascular health and mobility) and prevent the development of secondary conditions
- Lack of access or insufficient access to fitness and outdoor sports
- Day-to-day maintenance of mental health

Other Focus Groups

Participants in each of these focus groups reported problems that were not widely shared across other disability groups.

Those living with sensory disabilities (blindness, low vision, hearing impairments, or late-onset deafness) reported:

- Conflict of interest in physicians who diagnose and manage vision and hearing loss and who also promote and sell adaptive equipment
- The inability of disability-diagnosing physicians (audiologists and low vision specialists) to refer their patients to disability support groups and retraining services

Those living with hearing impairment reported:

- A wide range of complex obstacles unique to those living with hearing impairments, mostly resulting from the invisibility of their disability combined with the barriers it erected to interpersonal communication

Those living with cognitive diabilities reported unique problems which included:

- A wide range of fundamental health care access problems and unresolved health issues resulting from poverty

Results for Specific Women's Focus Groups

Women Living with Low Vision or Blindness

These participants (n=8) had several different degrees and types of visual impairment. They reported that loss of vision late in life was in many ways more challenging to one's social identity than vision loss that occurred in childhood or at birth; late vision loss conferred a loss of independence that in itself caused great emotional and mental distress. Those who faced low vision or blindness later in life rated fear of blindness and concern for their remaining eyesight among their highest health concerns and reported great anxiety around the adjustment process. Participants' three main concerns were:

- Professionals did not adequately help those just beginning to experience visual impairment to adapt to their new disability
- Gender bias among medical professionals, combining with bias against the blind, resulting in compromised quality of care
- Difficulty in getting physical exercise

In addition to these main issues, focus group participants also expressed concerns regarding:

- Violations of ADA among doctors and healthcare providers
- Healthcare providers untrained to interact with guide dogs
- Healthcare providers untrained to guide or assist the blind in moving around physical obstacles
- The difficulty of acquiring prescriptions to preserve remaining sight
- Conflict of interest in physicians who diagnose and manage vision loss and who also aggressively promote and sell adaptive equipment

The critically important problem reported by all participants concerned the gap between those professionals who diagnose loss of eyesight and those professionals who provide training in post-vision loss survival skills. Diagnosing physicians were reported to be unaware of the retraining services and support groups available to those who experienced vision loss in later life. Several participants explained that diagnosing professionals were often made very uncomfortable by vision loss disabilities and that they impeded their patients rather than assisted them in accessing the help and retraining needed in cases of vision loss. The resulting delay sometimes precipitated a series of bad outcomes (for example, fractures acquired from falls while trying to learn to walk without sight). Thus, the lack of networking between diagnosing physicians and retraining and support professionals was cited as a very serious problem for those who lost their sight late in life.

This group also reported many gender bias issues. For example, one individual had experienced spousal abuse; she noted that her doctors focused on her blindness as the presenting problem and overlooked flagrant physical signs of abuse. Others reported that their doctors and other healthcare providers often assumed that females living with disabilities would automatically be celibate, and that they did not receive information, testing, or treatment pertinent to sexual and reproductive health. Breast cancer was also reported as a health concern for several participants.

Learning to assess one’s own health status without vision (identifying bleeding, discoloration, etc.) was considered very important. Participants reported that doctors often don’t know how to address the tactile clues and skills visually-impaired persons needed to master in order to manage their own health.

Computer assistive technology for the blind was reported to be an excellent asset in acquiring health- related information and general information when it worked and a major problem when it didn’t. All informants concurred that getting technical support was very difficult and that the costs associated with acquiring and maintaining the technology needed could be prohibitive.

At least half of the participants were actively involved in fitness activities like T'ai Chi, Jazzercise, and weight training. Several individuals, however, reported difficulty in learning new physical activities without being able to see the person teaching them. Some reported problems with professional gyms—one person reported that her gym insisted that she hire a personal trainer to chaperone her at all times, although she felt that they should have accommodated her under ADA.

Women 45 and Older Living with Physical Disabilities

This focus group included women living with a range of physical disabilities (n=8). They reported five central concerns:

- Insufficient insurance coverage administered by unhelpful professionals
- Medical professionals and their staff being unfamiliar with or unwilling to adapt to the needs of the disabled
- Difficulty accessing and implementing preventive health care and health promotion, especially in the areas of fitness and mental health
- Lack of access to transportation, impeding access to medical care and independent living
- Difficulty finding and retaining skilled, reliable personal aides and assistants

Additionally, this group reported concern about:

- The high out-of-pocket costs of cutting edge therapy and CAM (complementary and alternative medicine)
- A great desire for improved access to CAM due to excellent results from CAM use (particularly massage therapy and acupuncture that offered lasting pain relief)
- Problems with VA facilities—frequently cancelled appointments, no direct phone contact with primary care physicians, and uneven access to fully accessible exam tables and mammogram machines

Insurance problems were reported to be a serious issue, especially in accessing adaptive technology and equipment. HMO referrals were identified as particularly hard to get; participants said that it was a constant struggle to be approved to visit needed specialists. Participants also mentioned that it was often hard to work with nurses and facility staff members who demand that individuals pick up referrals even when this is impossible due to disability and transportation constraints. Participants reported that, many staff members despite being told about this issue repeatedly refused to mail referrals, demanding that patients with serious disabilities appear in person to pick them up.

Exercise was desired by all, but presented a challenge especially because of transportation problems. Some respondents reported that the VA has a swimming pool and a wellness program, both of which were very useful for those individuals who had access to them. One participant mentioned that she enjoys swimming in a program sponsored by the MS society. For those with MS, air conditioning was reported to be a required part of any exercise environment, but insurers and government agencies treat air conditioning as a luxury, rather than a medical necessity. It was also emphasized that air conditioning was crucial for summer survival. Additionally, many forms of exercise were challenging or simply out of the question. Some noted that if one could afford a personal trainer and had transportation, exercise was possible; however, insurance does not reimburse the costs associated with exercise or ongoing preventive physical therapy. All participants expressed great anger about this.

Cooking, shopping, and food preparation were described as major challenges. Participants wanted to maintain healthy diets and avoid obesity and other "lifestyle-related" illnesses, but their disabilities made it difficult for them to cook for themselves. As a result, they often relied on other people's cooking skills. The Meals on Wheels food delivery program was reported to deliver non-nutritious, overcooked foods that appeared to be mush. Some churches that deliver meals, however, were noted to have healthier menus. Some participants were only able to microwave frozen dinners and eat low salt pre-prepared food. For these individuals, assistance was required in order to do anything else.

In terms of social support and positive mental health, companionship was reported to be accessible because of the telephone. Participants felt that as long as they made an effort to stay connected with the people they cared about, they could avoid isolation. Even companions or support groups that could only listen were reported to offer an important form of help.

Transportation was described as a serious, constant, and ongoing problem. Transit systems for the disabled were reported to be slow, unreliable, and often not actually handicapped-accessible. Moreover, many transit systems for the disabled only transport clients who are trying to get to medically necessary appointments. For other survival necessities like grocery shopping, participants said that they had to depend on public transit systems that appeared under-funded and barely adequate to meet the needs of the able-bodied. Accessibility issues abounded.

Many issues emerged in regards to accessing and managing aides and personal assistants. Qualified individuals were reported to be almost impossible to find and, once found, very hard to keep. Participants reported hiring illegal aliens and even resorting to asking people on the street about their availability. They also reported that it was difficult to get adequate coverage. Several informants emphasized that one could not afford to be "too fussy" or "complain too much" about assistants. Hiring help was reported to be extremely expensive—some participants paid up to $600 a week for help. Medicare and Medicaid were reported to cover too little, and if one is not poor enough to qualify for those programs and benefits, the Personal Assistance Services Program (PASP) is really the only resource available. Employing people was described as a lot of work and finding people who are safe to employ was named as a top challenge. However, one participant talked about her role as an official employer and how she has learned to hire and manage her own help without an agency. For her, this has been a positive experience, though a challenging one.

Other issues that were addressed included lack of STD testing or information by a physician. Participants did say they were receiving better gynecological care as post-menopausal women than they had received when they were of childbearing age. They also emphasized the critical importance of self-advocacy and networking.

Women 44 and Younger Living with Physical Disabilities

This focus group included women 44 and younger living with a variety of physical disabilities (n=7). They described four main areas of concern:

- Insurance, particularly difficulties associated with referrals and reimbursement
- Gender bias and its effect on health care
- Anti-disability bias in health care workers
- Preventive medicine/health promotion

Accessibility and insurance were the initial issues of main concern to be reported. Several participants expressed the desire for a cohesive, national health care system that encouraged communication among the variety of health care providers and services the focus group participants need. Finding a primary care physician with minimal knowledge about one's disability was reported to be difficult. Once found, individuals had to fight their insurance companies to gain access to the specialist to work with the primary care doctor. One participant reported very little success in accessing rare disease specialists through private insurance.

Even a participant with good (expensive, private) insurance found referrals to specialists who could work in tandem with a primary care physician difficult to acquire. The situation was worse for one young African-American woman in her late teens who was on Medicaid. She reported having no access to physicians who had any understanding of her disability. She described being dropped by her long time neurologist during a serious health crisis. She was told that this was because she had recently become an adult and needed to see an adult doctor, although she suspected it was related to low Medicaid reimbursement rates. The drop resulted in two hospitalizations and two operations because she could not find another specialist who would accept Medicaid in time to prevent serious health consequences. This individual also had questions about whether she could ever bear children, and reported that none of her clinic doctors knew whether she could safely have children or not. In sum, she has no access to this kind of information and no confidence in her clinic physicians. She also reported no continuity of care at the clinic she now must use because it is the only one she can access that accepts Medicaid patients.

A second very important issue was centered on physician attitudes towards female patients. All of the participants in this focus group agreed that physicians often refuse to take women's symptoms seriously, in ways that the participants felt were the direct result of gender bias. All reported having doctors refuse to believe them when reporting symptoms or having a specific condition (MS, for example) for which they were later diagnosed. Doctors had dismissed their patients' suspicions, sometimes for very long periods. For example, one individual with a rare genetic disease reported that her brother was diagnosed with her condition at the age of 15 while she herself wasn't diagnosed until she was 41. All of these participants agreed that they were not taken seriously because of their gender—and *all* believed that physicians had dismissed their experiences at some time in their history because they were women. One African American participant said that she had also experienced discrimination on the basis of her race, which compounded the discrimination she experienced on the basis of gender.

Several reported doctors behaving with insensitivity and refusing to speak directly to them while in consultations. They noted that doctors would speak to their husbands and/or companions instead. They reported feeling diminished, angry, and as though they "were worth nothing" because of this behavior. One participant, who was privately interviewed, was living with a physical disability that made her speech very difficult to understand; although she has no cognitive impairment and holds an advanced degree, people who don't know her frequently assume she has Down's syndrome on the basis of her speech impediment. While she reported good continuity of care and satisfaction with her disability specialists, she has often found that physicians who do not specialize specifically in her disability to be problematic. Many have assumed that she is not intelligent due to the communication barrier, and doctors tended to speak to her aide instead of directly to her during consultations.

Some, but not all, in this broad cross-disability group were interested in exercise and nutrition. Several women reported that their weight was an important issue, but that they simply could not sustain their weight loss efforts long enough to address the problem successfully without additional support and assistance. Others enjoyed walking or swimming, and felt that it was important. One woman reported having an active gym membership. With respect to nutrition, several participants mentioned having to work hard to eat healthy. A few said they did not care about maintaining good diet, though it was pointed out that the challenges particular to managing diet while working around a disability may have had something to do with this response. Difficulty obtaining accessible housing was reported to be a serious impediment to living a healthy life.

Companionship, especially that of family and a significant other, was deemed very important for mental health and spirituality was reported by some to be very important. Several women reported currently using or having used psychotherapy to address depression and other mental health issues.

Women Identifying as Late-Deafened or as Hard of Hearing

This focus group included women (n=12) who either became deaf late in life or who identified themselves as hard of hearing. The medical access issues faced by people living with these two kinds of conditions were, according to our focus group, very similar, so we discuss both groups in this section under the term "hearing-impaired." The complex challenges faced by this group fell into three broad categories:

- Difficulties associated with face-to-face communication
- Barriers presented by telephones, PA systems, voicemail directories, and similar technologies
- Challenges related to assistive technology access including the general unfamiliarity of hearing individuals with TDD and telephone relay systems

These focus group participants reported several obstacles to health care access that were unique to hearing impairment, as well as some that were common in other disability communities. Because hearing impairment is an invisible disability, they frequently encountered situations in which doctors and medical staff were talking to them and didn't know that the patient could not hear them. Even getting as far as the examination room can be difficult because hearing-impaired patients must position themselves carefully in order to see the nurses who will call out their names when it is time to be seen by the doctor. If they are not looking up and lip-reading when their names are called, they can be left to wait for long periods while the office staff assume that they have skipped the appointment.

Since many hearing-impaired people rely on lip-reading, the necessity of constantly reminding people to speak up and/or face them for purposes of lip-reading adds a strain to all communication tasks. Without a constant visible reminder of the patient's disability, even doctors and staff members who know about the patient's disability frequently forgot what adaptations caring for those with a hearing impairment required. They noted that even educating the medical office staff and doctors in person could be insufficient, because some doctors forget matters of telephone protocol and there is such a high turnover rate among office staff.

Moreover, not all doctors, nurses, and staffers have patience with the needs of the hearing-impaired. Hearing-impaired patients often found themselves in undeserved conflict with people who have written them off as non-cooperative or non-compliant. Focus group participants reported doctors shouting at them that they "could not handle" the patient's hearing loss. Some said that their doctors insisted that they bring a hearing person with them, so that the doctor could speak to the hearing person as if the actual patient were not even there. Those people living with hearing loss reported being condescended to or ignored and spoken to as if their disability meant they were "…stupid, not fully adult, or not fully human" (in their own words).

There are some situations in which hearing-impaired people reported needing to rely on spouses, relatives, or friends to accompany them to medical settings. Under circumstances that called for the health care provider to wear a face mask, for instance, companions are crucial. Participants explained that surgery is especially terrifying, because often doctors will not compromise sterile surgical conditions for the sake of the patient's need to lip-read. This problem pertains to any kind of health care provider who uses a sterile mask, including dentists and dental hygienists. Some reported similar but less serious problems lip-reading with medical personnel who had thick accents or moustaches.

One focus group participant reported that an anesthesiologist who knew that she was hard-of-hearing and could not hear him came to see her moments before her surgery to tell her what he would be administering. He would not remove his mask to speak to her, despite her repeated protestations that she could not hear him, and her repeated requests for her hearing aid, which had been taken from her in preparation for the surgery. Had her husband not been present to hear the anesthesiologist, the patient would have been administered a drug to which she knew she had a life-threatening allergy.

The stress and physical discomfort of the medical need necessitating the visit in the first place, compounded by the stress and social discomfort of trying to cope with diminished ability to hear what people say, was described as exhausting and discouraging, and stress-related illnesses were reported to be very common among hearing-impaired people. Additionally, participants said they must protect what little hearing they may have left from ototoxins and ear infections, requiring even more education of doctors who may already feel burdened by the level of education necessary simply to communicate successfully with a hearing-impaired patient. Bad hospital experiences involving these kinds of issues left some participants too terrified to return to the hospital, or even to routine appointments.

Hearing-impaired participants found it difficult, and sometimes impossible, to use technologies such as telephones, voicemail systems, and directories. Likewise, participants felt that hearing people were unfamiliar with the technologies they rely on, to the point of being unable to respond to them. For instance, many focus group participants said they found it so difficult to navigate medical offices' automated telephone systems that it was easier and less time-consuming to drive to the doctor's office to make appointments.

Telephone barriers were reported to have even more adverse effects than in-person communication barriers. Focus group participants who had made 911 calls reported problems with 911 operators that had resulted in potentially life-threatening delays. Participants explained that TDD and telephone relay systems can, under some circumstances, be very useful to hearing-impaired people, but those who still have their hearing are often so unfamiliar with TDD or relay operators that it is, again, easier and less time consuming to attempt face-to-face communication than it is to struggle with the adaptive technology.[3]

Participants also reported that hearing-impaired patients who derive some benefit from hearing aids may have those hearing aids taken from them for medical procedures. Participants believed that the aids are taken far more frequently than is necessary, and noted that often the patient has to advocate strenuously for him or herself to get them returned after the procedure is completed. While the patient goes without the hearing aids, the importance of lip-reading, already a challenge, is even greater because they may be unable to distinguish what is being said on a hospital PA system. Thus, they may not hear nurses' efforts to speak directly to them when they are in hospital beds.[4]

Participants pointed out that posting a reminder at the nurses' station of a patient's hearing impairment, allowing patients to keep hearing aids, providing an amplified telephone, and giving patients special buttons reminding nurses of their hearing impairment can make all the difference in matters like these. However, emergency room admissions are especially terrifying because there may be no opportunity to even ask for these adaptations.

Getting access to hearing aids, telecoils, and other assistive devices that are very expensive to buy is a problem. Participants reported that $6,300 per aid is top of the line, $4,700 is middle-of the road, and less than that wastes money on goods that will not actually address one's needs. Insurance will not cover the cost of hearing aids, even in part.

Another issue raised centers on audiologists who are isolated from the disability support community, resulting in a multi-year delay between diagnosis and the location of appropriate support and

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[3] With these two means of adapting telephone use, there is always a delay in communication, and the delay can be off-putting to hearing people. Participants reported that some medical personnel simply refused to take such calls. With the relay system, it is necessary to trust that the relay operator is interpreting both parties accurately; this can be a challenge, because relay operators are not medical experts, and they can get important things wrong even if they are initially expressed accurately by both the patient and the doctor.

[4] Several focus group participants reported being left isolated in hospital rooms for long periods of time when they were trying to buzz the nurses' station for urgently needed help. In response to the patient's having hit the panic button, the nurse would buzz back on the intercom and ask what was wrong. The patient in this often-repeated scenario would not hear the intercom and would not answer. The nurse, assuming that the patient had hit the distress call unintentionally, would take no action at all. In one case, a patient with a broken IV remained unattended for seven hours before someone came to respond in person to her calls for assistance.

support services. During those years, hearing-impaired people often face isolation, depression, anxiety, and stress-related illness arising from the necessity of managing their condition alone until they find their way to communities of people with similar conditions who can offer them mutual support, information, and advocacy.

Focus group members felt that audiologists are not educated about how to refer people to help or why it is absolutely critical to do so, although audiologists are the closest things hearing-impaired people have to experts on their condition. Furthermore, since audiologists sell expensive equipment, it is hard to assess whether a specific recommendation for an assistive device is really appropriate to one's needs, or whether the recommendation is motivated by the audiologist's opportunity to profit. Particular issues about which audiologists are insufficiently knowledgeable include the reasons why a person needs two hearing aids instead of one and why a telecoil switch is so critically important.

Men's Focus Groups

Men Living with Low Vision or Blindness

This focus group (n=7) was comprised of men living with either low vision or total blindness. They reported six main areas of concern:

- Transportation, in every area of life
- Difficulties dealing with medical practices as a whole unit, and in particular with the staff
- Conflict of interest among helping professionals
- Access to preventive health
- Mental health
- Access to sports and outside fitness activities

These men reported transportation challenges to be their first and most constant concern. Lack of access to convenient, reliable transportation was repeatedly mentioned as a barrier in reaching appointments with health care providers and in maneuvering through their facilities. In addition to transportation for health care, these men indicated that not being able to drive conflicts with the gender roles usually ascribed to men. Because it limits independence, the inability to drive conflicts with expected male behavior, such as working in the mainstream economy, driving wives and girlfriends, and taking the lead in initiating activities of all kinds. These gender role conflicts cause stress and, therefore, present a mental health challenge.

As mentioned during the women's focus group, these men also experienced medical providers' and staff's unwillingness to adjust to the needs of individuals with low vision. One individual reported being denied care at a hospital because he came to the facility alone and did not bring a family member with him to fill out the required forms. He explained that the problem was not with the physicians themselves, but with intake staff and bureaucracies that refused to accommodate their routines to the demands of his lack of vision and insisted that he always bring a sighted person with him to read, write, and guide him through the process of obtaining care. This individual tried to file a complaint against the facility, but was told that he would need to travel a long distance and fill out a complaint form—neither of which he could do alone.

Privacy concerns were also reported in connection to medical appointments. It was explained that visually-impaired individuals can only respond to the receptionist verbally—not through writing—so everyone in the office can hear what they have to say. For many men, this was a source of discomfort.

Providers who were also venders of assistive devices were raised as an issue within this group. Several men reported discomfort with doctors who became salesmen as they could not tell if these professionals were making impartial recommendations. These participants perceived that vision specialists might not even know what would be best for some individuals, or that they might know but refrain from recommending those items they do not carry.

Several focus group participants reported that religion and spirituality as well as mental health were important issues. In particular, depression was reported to be a serious problem that often remained un-discussed. Men, in particular, were reported to be uncomfortable and unwelcoming of discussions about depression. Because of the stigma associated with mental illness, one participant called the focus group facilitator back to discuss the problem, saying that it was impossible to be frank within a focus group setting. This informant noted that both vision loss later in life and other life issues in combination could lead to serious depression. This man indicated that discussing depression and mental health, even within support groups for visually impaired individuals, was often difficult. He emphasized that mental health and access to mental health care is very important but that gender roles inhibit men from discussing these facts.

A strong desire for access to outdoor fitness and fitness and sports in general was also expressed. Several participants were active at gyms or played beep ball, a ball game for both blind and sighted individuals. Finding a place to play has been hard to do because land owners are afraid of their possible liability should someone get hurt.

These men also reported difficulty in maintaining a good diet because few resources are available in Braille or in another alternative format. While Weight Watchers support materials are available in Braille, information on diabetes, for example, is not easily found in that format. Calorie counters are also unavailable in Braille. Nutrition labels are never available in Braille so it is hard to keep track of what one is eating and make the best nutritional choices when shopping.

Men 45 and Older Living with Physical Disabilities

This focus group included men (n=5) 45 and older living with physical disabilities. The biggest issue reported was staying healthy while aging with a disability. They reported some deterioration in their conditions especially among the older participants. Their top three concerns included:

- Physical exercise, health promotion, and preventive medicine especially as they age
- Maintaining positive mental health
- Access to doctors knowledgeable about their disabilities, a handicapped-accessible office, and a disability-educated staff

In regard to formal exercise programs and preventive physical therapy, only some participants reported having access (due to insurance coverage) to strong preventive physical rehabilitation programs. One older participant uses a hand-driven stationery bicycle at home, while another stays active with outdoor sports. Non-mobile participants worried a great deal about their cardiovascular health and cholesterol as they age. Urological health was also a very serious issue among those who use wheelchairs.

Community and spirituality were reported to be very important components of participants' coping strategies, especially as they age. Participants reported many frustrations and obstacles in their daily lives, and all agreed that they made conscious, systematic efforts at managing the psychological and emotional impacts of those frustrations. Lacking reliable access to transportation, they conducted many aspects of their social lives by telephone, and called on friends in the disability support community when they encountered setbacks.

Like women living with physical disabilities, these men felt that aides and assistants were extremely important. The oldest participant reported that cooking, eating, and transferring from bed to chair were serious problems. He explained that he uses personal assistants and depends a great deal on his aides. On those days when he has no aides, he struggles. He described persistent worries that he will fall and have trouble getting to the phone. So far, every time he has fallen, his dog has brought him the phone and he has been able to call the police and get help getting back into the chair.

As in the women's focus groups, these men also reported that it is extremely difficult to get a referral to a quality care provider in an accessible location who is familiar with one's disability. Several men reported having no primary care doctors because of these difficulties. Some individuals reported difficulty in getting help from the Commission for the Blind because Commission agents are not always available in all counties.

Men 44 and Younger Living with Physical Disabilities

The members of this focus group (n=5) were remarkably active, despite the many challenges that they faced. All of them had some kind of job, all had at one time or another engaged in a serious effort to maintain health through athletic activities, and several had important roles in advocacy organizations for the disabled. Their three chief issues involved:

- Difficulty finding and keeping doctors who were knowledgeable about their disabilities
- Inadequate insurance policies that disrupted continuity of care, did not cover preventive measures, and under-funded crucial assistive devices
- Developing and maintaining exercise regimens to preserve their mobility as they age

Their chief complaints involved access to physicians and the attitudes of these physicians. These men found it very difficult to find doctors who were knowledgeable about their disabilities (cerebral palsy was particularly problematic) and, due to insurance issues, it was often impossible to keep good doctors once they found them. They also reported that it was hard to get treatment for health problems not directly related to the disabilities, as doctors often focused on the disability rather than the actual presenting problem. They expressed frustration about the constant necessity of educating their doctors, who should have been the experts on their conditions. For instance, participants said they often educated doctors about the necessity of writing a prescription for assistive devices, such as crutches, in order to activate insurance coverage.

These men discussed two main complaints about insurance coverage: inadequate coverage for assistive devices (such as crutches) and inadequate preventive care coverage. Specifically, they could only get coverage after something had gone wrong, such as an injury or complication. Moreover, they felt that they would have been better able to maintain their ability to contribute meaningfully to society (an important element of their personal identities) had they had access to physical therapy as a matter of course. Instead, they were covered only for a limited number of physical therapy sessions for rehabilitation from injuries that could have been prevented had they had access to better preventive/routine care.

All of these men expressed concern about preserving and extending their mobility, especially as they age. Having insufficient access to physical therapy, they had varying success with maintaining their fitness. Some had attempted to join commercial gyms or the local YMCA, but reported that trainers were completely unaware of disability issues, and were for the most part unwilling to learn. Thus, they often had to learn how to modify exercises and games designed for the able-bodied without assistance. Some did have childhood experiences with the Special Olympics, with wheelchair basketball, with dedicated scout masters in the Boy Scouts who worked with them to make athletic pursuits possible, and those were treasured memories. One member of the focus group had become a very successful referee and got his exercise by officiating at sports in which he could not be a competitive player. These men devoted a great deal of time and attention to athletic pursuits much because they felt their future mobility depended on it. For them, finding and maintaining regular exercise was a matter of survival.

Mixed-Gender Focus Group

Men and Women Living with Cognitive Disabilities

This focus group (n=29) included 15 women and 14 men living with cognitive disabilities. We conducted this focus group in person with members of a pre-existing support group at their regular meeting time and place. As some of these individuals were not living in the community, they may not share the same issues as those in the community. Participants described the following important areas of concern:

- Access to expensive prescription medications
- Access to both primary and specialty health care and maintaining continuity of care (when primary care and family physicians stopped accepting Medicaid)
- Maintaining privacy during consultations
- Accessing preventive health services and supports
- Eating a healthy diet
- Access to safe and affordable exercise opportunities

Among all of the focus groups, this group reported the most fundamental health care access problems and the most basic unresolved health care issues. Many of the problems reported by these individuals were related to their extremely low incomes (all were working at low paying/minimum wage jobs without health benefits) and their dependence on health care providers who take Medicaid. Many of the participants reported losing primary and specialty care physicians they had seen for years when those providers stopped taking Medicaid. Access to specialists was also reported to be extremely limited because of their Medicaid status. Participants pointed out that dentists in particular were very hard to find. Consequently, many said they traveled a long way to a clinic in Mountainside willing to see them and, because of this, transportation had become a serious issue. Although most participants reported working with social workers and agencies to get to clinics and doctors as well as accessing transportation, the process was described as very difficult. Some had been forced to change physicians three or more times; thus, they lacked any semblance of continuity of care.

Poverty also had serious impacts on participants' ability to eat well and exercise. Several reported that they needed access to a nutritionist that could help them improve their diets on a very, low budget—as low as $40 a week. All participants said that they wanted to improve their diets, but felt that they did not know how, especially with so little money. Several asserted that what they really needed was a higher income in order to be able to afford to buy healthier, usually more expensive, foods.

Similarly, exercise was difficult because of income constraints. Walking was the main form of exercise reported, but this was not always a safe alternative. Many lived in poorer neighborhoods where they felt that it was unsafe to walk, especially in the evenings when they had free time. None had enough disposable income to buy home equipment, nor could they afford or access gyms.

Privacy was also described as an important issue in two ways. First, many participants must go into consultations with their social workers and use a "consult sheet" to list their conditions and treatment plan recommendations because a social service agency is tracking both their medical treatments and their adherence. This information is placed on file with the agency and/or the state. Respondents reported that sometimes these staff members expressed resentment about the added bureaucratic burden of filling out the sheets. Many felt this burden, in conjunction with low Medicaid reimbursements, encouraged physicians to drop Medicaid-insured patients with cognitive disabilities from their practices. Second, participants preferred not having a social worker in their consultations to translate their doctors' recommendations for them. They felt that the onus should be on doctors to learn how to speak plainly and communicate with them directly. They reported that although the medical jargon was sometimes difficult to follow, they resented doctors' assumptions that they would be unable to understand anything that they were told. These individuals asserted that they would be able to follow and understand plain speech about their conditions. Not surprisingly, we found that about half of the focus group said that they were unhappy with their doctors, lack of trust being a critically important issue for them. Many had had bad experiences with physicians and did not trust their healthcare providers or have any confidence in the care that they received.

Prescriptions were reported to present a huge economic problem. Without prescription coverage programs, these individuals reported that they often could not afford needed prescriptions. Instead, they went without them, choosing to buy essentials like food instead of medicines.[5] They were angry about the high cost of prescriptions and want to know why they are so expensive.

Two women living with cognitive disabilities were interviewed outside of the focus group setting. Unlike the focus group participants, both were privately insured and employed at positions earning higher wages. These women had a very different perspective than their focus group peers, reinforcing the notion that poverty was at the core of many of the problems reported by the focus group participants. One had HMO coverage and reported being very satisfied with her care. She reported excellent continuity of care, good doctors, access to gynecology care and access to prescriptions. The second felt strongly that she wanted to avoid HMOs and maintain her freedom to see the specialists she liked.

Although they were satisfied with their care, neither woman had ever been offered STD testing or asked about birth control preferences (both women were in their late 30s). They were surprised at the notion that it was a primary care physician's responsibility to do this. One reported longtime difficulty in getting a baseline mammogram because she could not get her appointment approved. She had been turned away several times at the mammography facility after making appointments.[6]

State-wide Survey Results

Due to potential gender differences, we analyzed the data in two ways**.** First, we present the overall findings. Second, we present any significant differences by gender. Most of these surveys were completed by persons living with a disability themselves (63.4%), while 21.7% were completed by a family member or a friend, and 18.8% were completed by paid caregivers serving as the proxy. Women were significantly more likely to respond for themselves than were men (Chi-square= 7.2, p<.05.) In Table 2, we see that most respondents were female, unmarried, and had an average age of 47.2 years. Women (mean age=49, s.d. =15.9) participants were significantly older than their male counterparts (mean age=44, s.d. = 16.7) (p<.01.) Approximately one-fourth had completed high school with about half having completed at least some college. Most were not working. Almost forty percent had children.

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[5] Some said that they had a discretionary spending budget of only $40 a week from which they purchased food.

[6] She reported having another mammography appointment soon and was dreading it because she feared that she would be turned away again. She could not explain why this was happening and no one had attempted to explain it to her.

Table 2. Personal Characteristics

Gender	62.8% Female; (n=293)
Age (n=288)	Average= 47.2 years (s.d.= 16.4) Ranging from 17 to 88
Marital Status (n=293)	20.4% Married/Living with Sign. Other 7.5% Widowed 16.4% Separated/Divorced 55.6% Single/Never Married
Education (n=286)	16.1% Less than High School 28.0% High School 6.3% Technical or Vocational School 23.8% AA College Degree 25.9% BA College Degree or higher
Working Status (n=287)	15.0% Full-Time 21.3% Part-Time 63.8% Not Currently Employed
Children (n=291)	39.5% have children Ranging from 1 to 8 children: Average=2.4 (s.d.= 1.3)

In order to better understand the range of disabilities reported by our respondents, we asked them to describe their disabilities. The most prevalent types of disability were Cerebral Palsy (11.6%), Spina Bifida (10.5%), visual impairments (9%), and other types of physical disability (including reporting only a "physical disability" (15%) (see Figure 1). There was a significant difference by gender with more women than men reporting having multiple sclerosis, cerebral palsy, visual impairments, hearing impairments, and mobility impairments (Chi-square=30.8, p<.01). Over half of our respondents resided in their own homes or apartments, and about one fourth reported that they live in someone else's home (see Figure 2). Less than ten percent respectively resided in another setting that included an off-site supervisor or in a group home housing an on-site supervisor. Most lived with a friend or family member, but one-third lived alone (see Figure 3). Only two percent lived with a paid caregiver.

With respect to health care service experiences, in the past year respondents reported seeing a variety of professionals (see Figure 4). The most frequently used health care providers were Dentists (72.1%), Family Practitioners/General Practitioners (66.3%), and Ophthalmologists/Optometrists (60.2%). Probably due to differences in disability, significant gender differences were reported for those seeing Chiropractors (Chi-square=7.2, p<.01), Podiatrists (Chi-square=8.7, p<.01), and Radiologists (Chi-square=12.5, p<.01).

Regarding service use issues, only one quarter (24.4%) belonged to a health maintenance organization. Most respondents reported having Medicare (56.1%) or Medicaid (41.8%) (see Figure 5). More than half of the respondents reported that they never had problems getting health care services (32.5%) or rarely had problems (25.2%) (see Figure 6). Almost six percent, however, reported that they *always* had problems. The types of problems reported included getting the doctor visits one needed (16%), getting needed services (19%), accessing those products needed in order to function more independently (18.7%), and getting transportation (22.1%) (see Figure 7).

Respondents were also asked about their experience with providers (see Figure 8). Most reported that they perceived that their health care providers were uncomfortable with their disability (78.2%). About one-quarter said they avoided appointments because of their experience with providers (24.1%); one-fifth reported that providers lacked knowledge about their disability (20.6%).

With respect to self-perception of health, respondents were asked to rate their overall health. Overall one-third rated their health as good (36.6%), while one-quarter rated it as either very good (24.7%) or fair (24.7%). Less than five percent (4.5%) rated their health as poor. Women reported significantly poorer health (Chi-square=12.1, p<.05), but there were no significant differences between proxy respondents and persons who responded for themselves (see Figure 9). As a comparison, a random sample of US adults reported higher levels of self-assessed health (63.8% rated as excellent or very good; 24.5% rated as good; and 11.6% rated as fair or poor) (National Health Interview Survey (NHIS), 2000.) In 2002, the Behavioral Risk Factor Surveillance System (BRFSS) also collected data on self-assessed health from a New Jersey sample of adults. The general adult community health rates for New Jersey were: 23.3 percent reported excellent health, 32.3 percent reported very good health, 29.7 percent reported good health, 10.7 percent reported fair health, and 4.0 percent reported poor health.

In order to compare our respondents to the general population, we included several other BRFSS questions in our survey. One BRFSS question asked: “How often in the past 30 days had the respondent felt that their health was not good?” Among our respondents, 58.4 percent reported at least one “not good” day in the past 30 days. While 33.7 percent of the BRFSS sample reported at least one “not good” day (see Figure 10.) Moreover, our study respondents reported more “not good” days than the BRFSS sample of NJ adults

We also asked a number of questions related to activities such as tobacco and alcohol use. Most respondents were non-smokers. Only 11.1 percent were currently smokers, while 22 percent reported that they were former smokers (see Figure 11.) Comparatively, 19 percent of the NJ BRFSS respondents and 23.1 percent of the national sample (NHIS) identified themselves as current smokers. Regarding alcohol use, about one-third (34.2%) of study respondents reported having at least one drink in the past 30 days, with men reporting 1.6 drinks (s.d. = 1.9) and women reporting 1.0 drinks (s.d. = 0.9). In comparison to the BRFSS sample of NJ adults, our respondents reported significantly fewer days per month during which they drank alcohol (see Figure 12.)

We also surveyed people regarding their mental health (see Table 3). Specifically, we asked: "How often in the last 30 days did you feel sad, depressed or blue?" and "How often did you feel worried, tense, or anxious?". More than two-thirds (65.8% and 70.9%) of the respondents reported these feelings at least one day, with average number of days with depression being 7.9 (s.d. =10.2) and the average number of days with anxiety being 9.6 (s.d. =11.2). The 2002 New Jersey BRFSS data also reported the number of days during the past 30 days in which respondents' mental health was not good. While not an exact question, this measure does provide some basis for comparison. Compared to the NJ BRFSS data, our sample reported significantly more days of mental health symptoms (See Table 3).

Table 3. Mental Health Characteristics

Sample	Question	No Days	1-2 days	3-7 days	8-29 days	30 days
Community Sample of Individuals with Disabilities (n=275)	Sad, blue, or depressed during the past 30 days	34.2%	12.8%	20.4%	21.3%	11.3%
	Worried, tense or anxious during the past 30 days	29.1%	10.0%	21.2%	22.8%	16.9%
NJ BRFSS Sample (n=5841)	Mental health was not good during the past 30 days	68.9%	9.1%	9.8%	7.8%	4.3%

Using the BRFSS question about the number of days that poor physical or mental health prevented the respondent's engagement in usual activities, we see that women responding to our survey reported an average of 9.1 days in answer to this question (s.d. =11.1) while men reported an average of 5.2 (s.d.=9.7) days (see Figure 13) Both women and men in our survey reported more days of activity interruption than did in the NJ BRFSS sample.

Diet and exercise represent another major aspect of health promotion and health maintenance. About half of our respondents reported that weight was a serious concern for them (see Figure 14.) Women were significantly more likely to report weight as an issue than were men (Chi-square= 5.5, p<.05); they were also more likely to report being overweight or needing to lose weight (Chi-square= 4.6, p<.05.) Many people reported taking vitamins (60.5%), eating a low fat diet (41.5%), and avoiding fried foods (39.1%) (see Figure 15). Fewer individuals reported using meal replacements (6.1%) or meal supplements (4.8%). Women were significantly more likely to report adhering to a low salt diet (Chi-square= 4.7, p<.05.)

A wide variety of exercises were also reported (see Figure 16), with aerobic or cardio exercise (40.1%) and stretching (32.7%) being reasonably common. Women were significantly more likely to do stretching (Chi-square= 3.9, p<.05.) and chair exercises than were men (Chi-square= 5.7, p<.05.) The average number of days exercised was 4.1 (s.d. = 2.0) and the average time spent exercising was 4.6 minutes (s.d. = 6.5). Overall, 69 percent of people with disabilities reported engaging in exercise. In comparison, 74.0 percent (n=6170) of NJ BRFSS respondents reported participating in a physical activity during the past month. One possible goal of physical activity is the preservation or maximization of mobility. Almost two thirds (59.6%) of our survey respondents reported that this was a serious concern for them (see Figure 17), with women significantly more likely to report mobility issues than men (Chi-square= 6.9, p<.01.). While only a few people specified the nature of their mobility issues, the problems that they reported included:

- a desire for independence (10.2%)
- difficulty doing necessary tasks (8.2%)
- problems with balance/standing/walking (5.8%)
- coping with the progression of the disability (5.1%)
- fatigue/weakness (4.4%)
- experiencing pain (2.4%.)

Recommendations

We recommend that several key health issues commonly mentioned across all focus groups be initially addressed. These recommendations include:

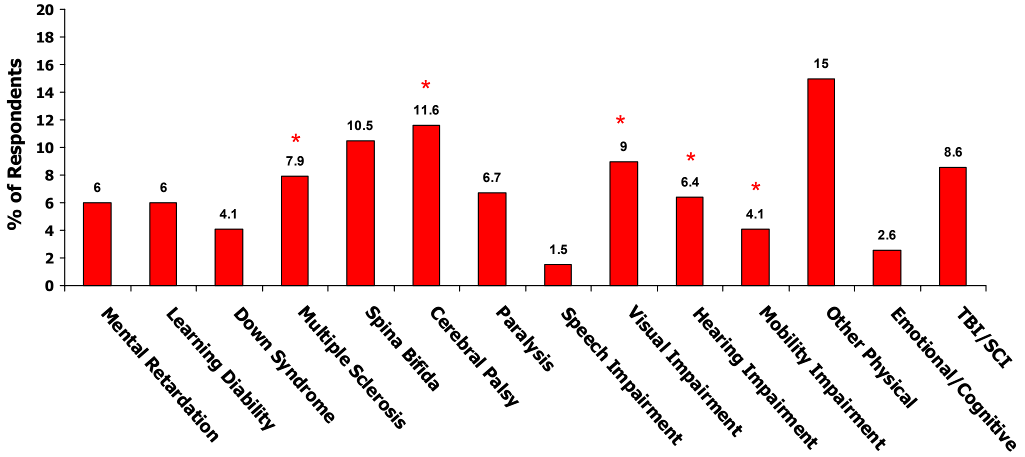
- Educating doctors, other professional healthcare providers and intake staff regarding disability and gender bias issues,
- Addressing inadequate coverage for assistive devices, health promotion and prevention, and difficulty accessing specialty care,
- Developing ways to assist individuals to find doctors who are knowledgeable about disabilities and encourage doctors to be more open to working with these individuals,
- Expanding ways to improve and maintain positive mental health, especially for men

- Encouraging and educating disability-diagnosing physicians (audiologists and low vison specialists) to refer their patients to disability support groups and retraining services
- Providing additional support for maintaining healthy eating and physical exercise habits in order to prevent the development of secondary conditions

Additionally, as a number of the problems faced by individuals with disabilities concerned their interactions with various care providers (physicians, medical staff, service providers, and fitness professionals) it may be worthwhile to initiate discussions or interviews with these individuals in order to better understand their perspectives and discover what could be done to make their interactions less challenging.

Figures

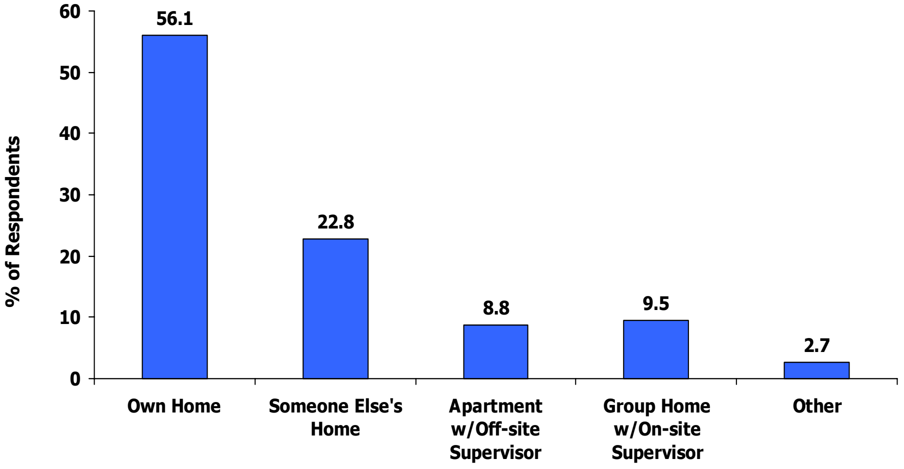
Figure 1: Type of Disability



N=292

*Significant Gender differences

Figure 2: Living Situations



N=294

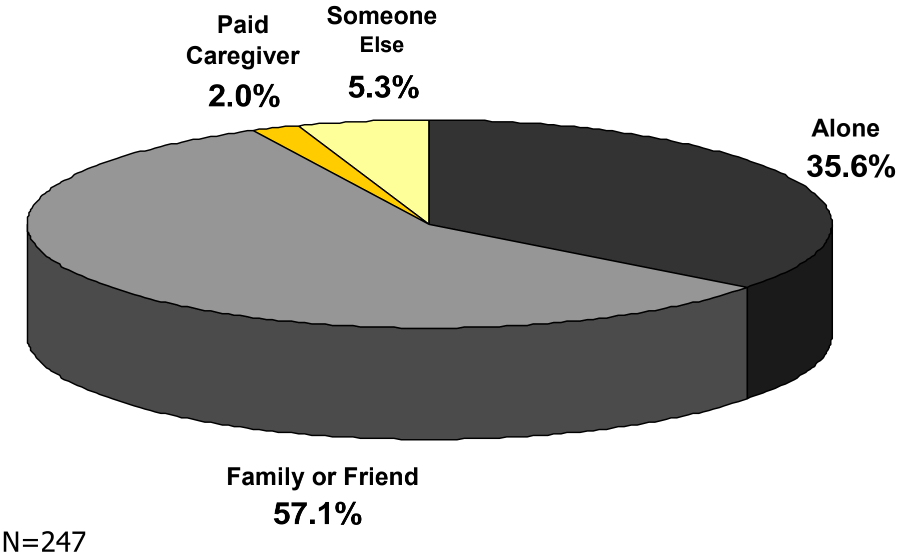


Figure 3: Living Arrangements

N=247

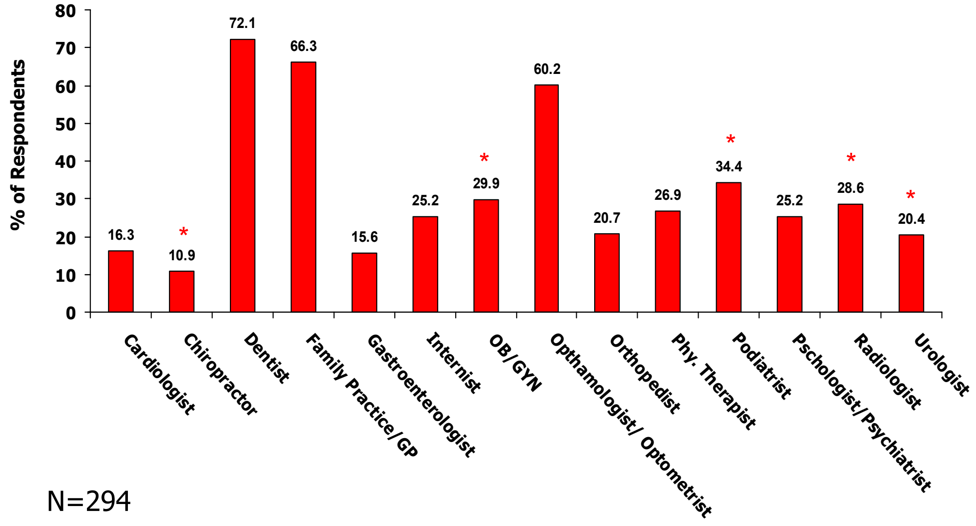
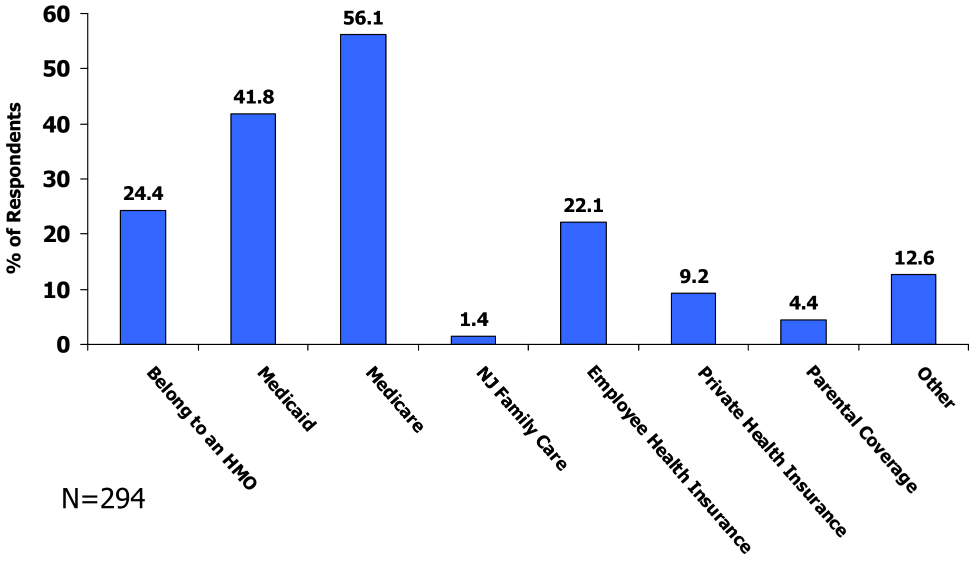


Figure 4: Providers seen during the Last Year

N=294

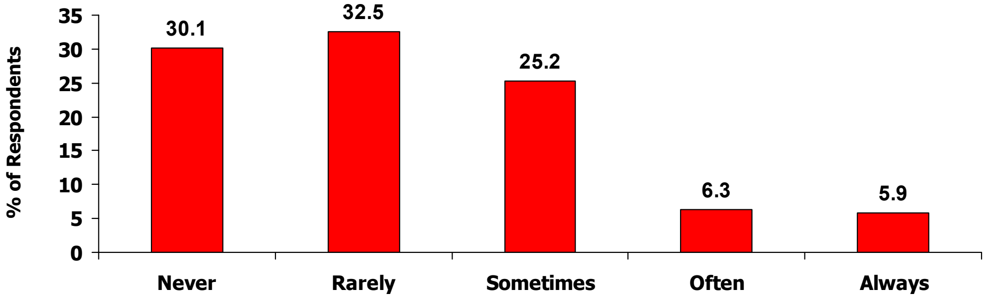
*Significant differences by gender

Figure 5: Health Insurance Information



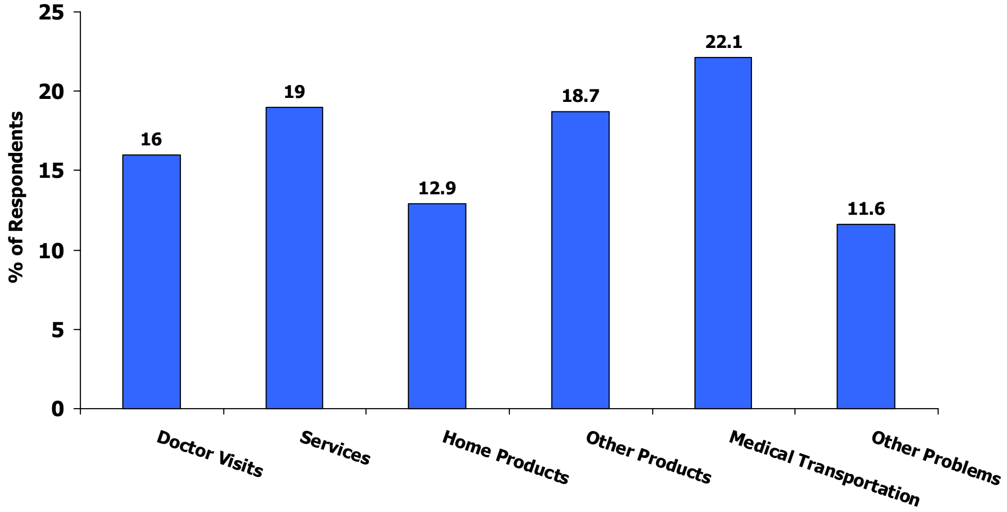
N=294

Figure 6: Percent of Respondents Reporting of Problems Getting Needed Health Care Services



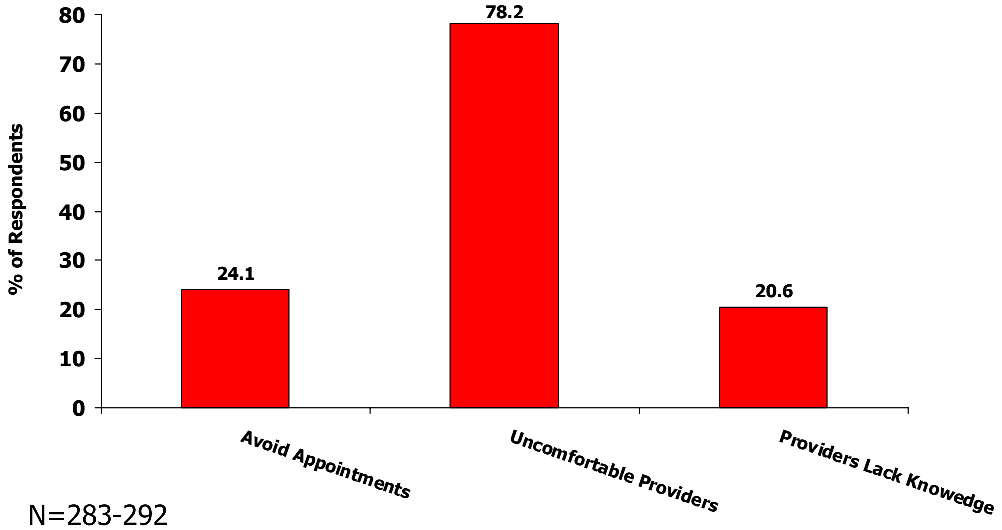
N=286

Figure 7: Service Problems



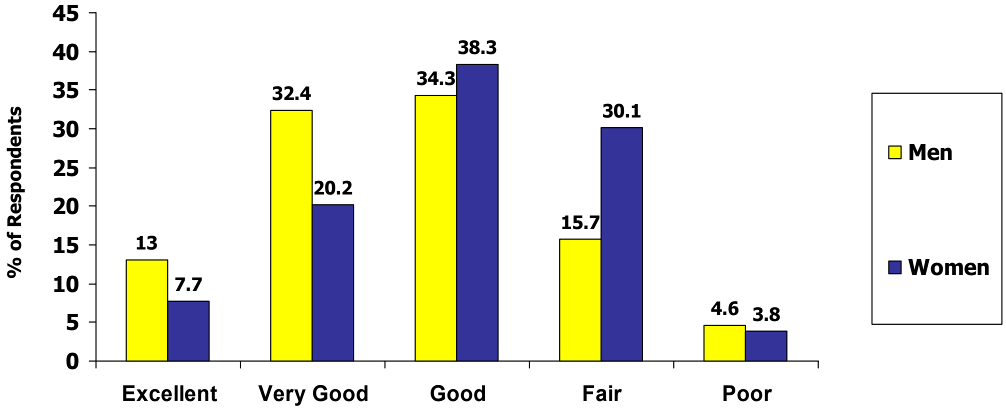
N=294

Figure 8: Experience with Providers



N=283-292

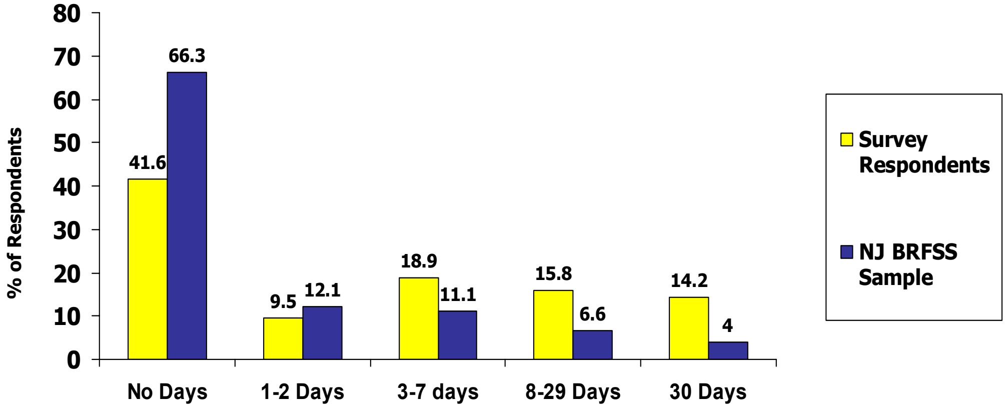
Figure 9: Self-Rated Heath by Gender*



N=292

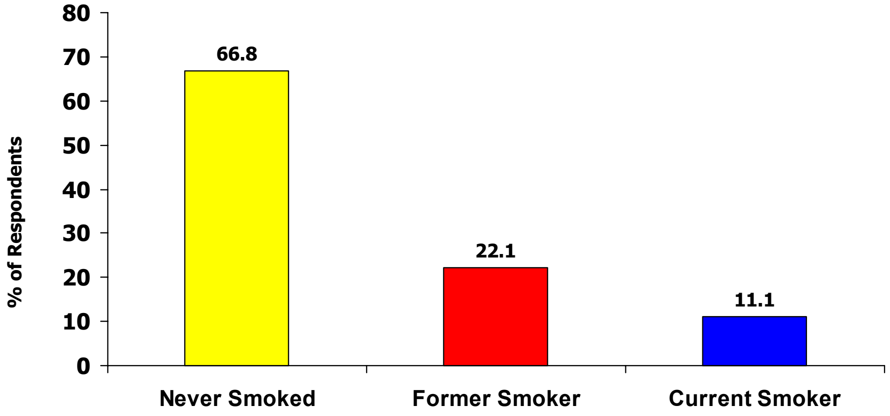
*Significant differences by gender

Figure 10: Number of days reported as "not good" : Survey Respondents and NJ BRFSS Sample



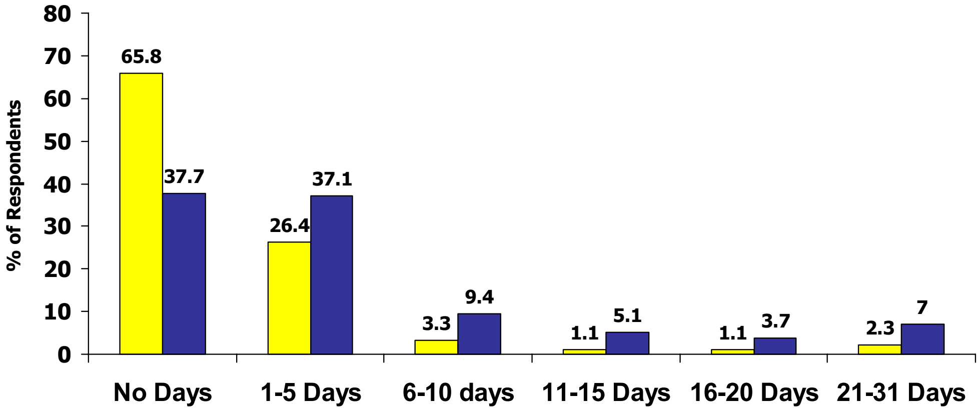
Survey Respondents N=274, mean =7.7 days, s.d.=10.8
BRFSS Sample of NJ Adults N=6170

Figure 11: Tobacco Use



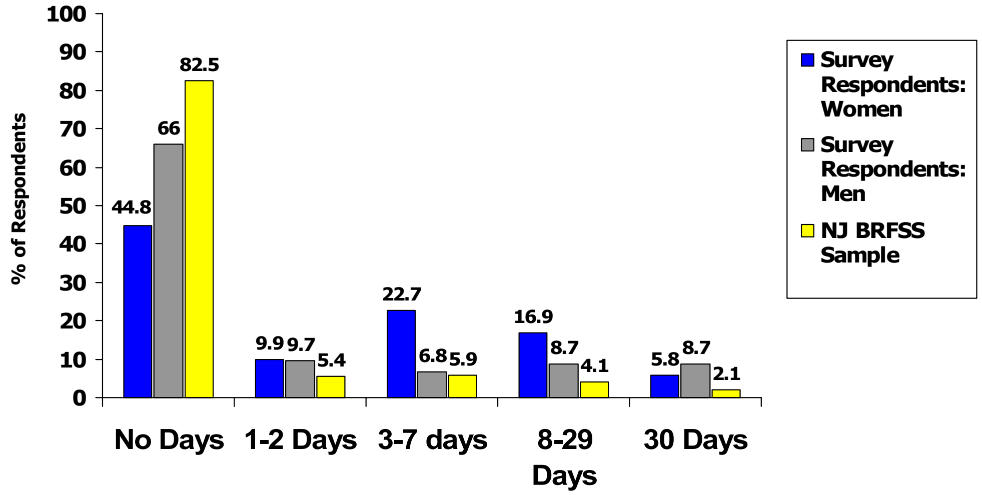
N=289

Figure 12: Number of days reported having at least one drink : Survey Respondents and NJ BRFSS Sample



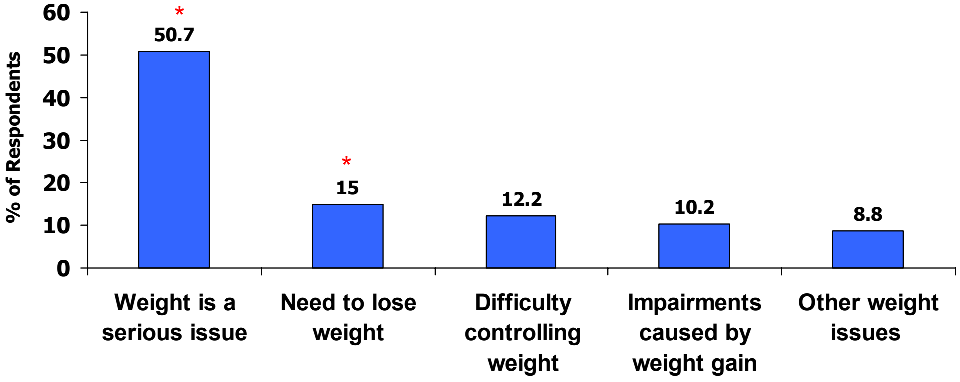
Survey Respondents N=269, mean =2.0 days, s.d.=5.1
BRFSS Sample of NJ Adults N=6170

Figure 13: Number of days poor physical or mental health prevented usual activities: Survey Respondents and NJ BRFSS Sample



Survey Respondents N=275, significantly different by gender
BRFSS N=5919

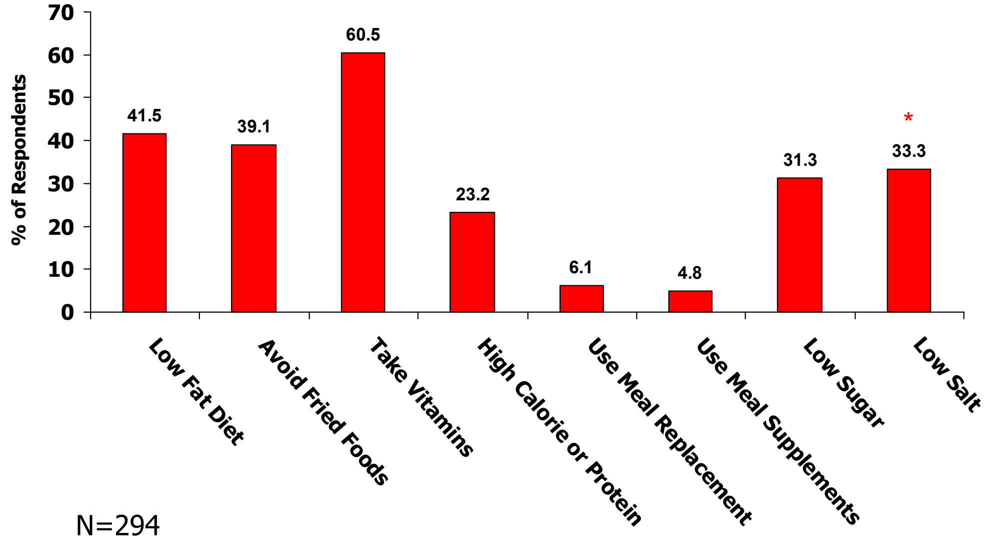
Figure 14: Weight Gain Concerns



N=288

*Significant differences by gender

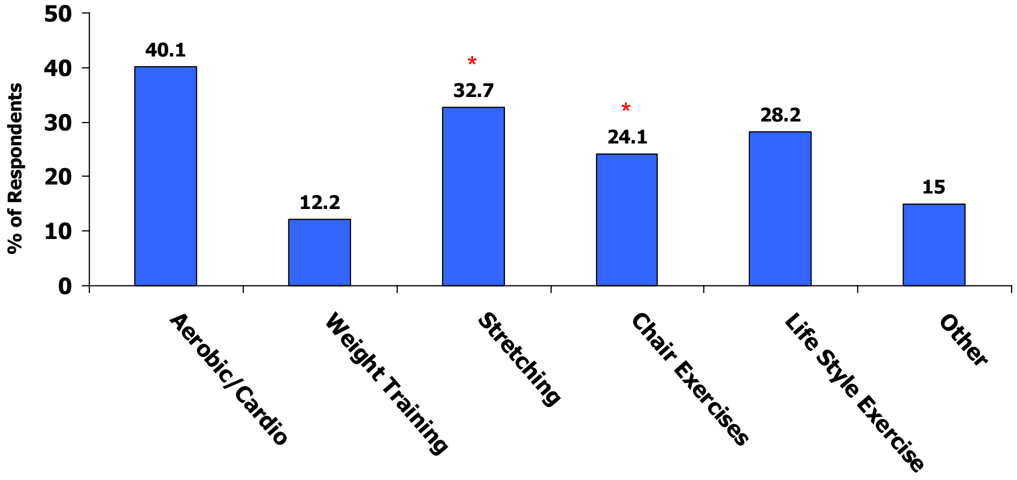
Figure 15: Dietary Activities



N=294

*Significant differences by gender

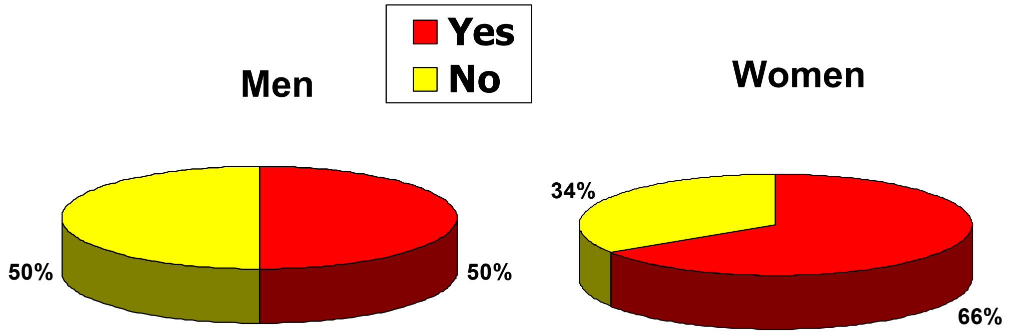
Figure 16: Exercise and Fitness Activities



N=294

*Significant differences by gender

Figure 17: Preserving or maximizing mobility is a serious concern by gender



N=272

*Significant differences by gender