

FINAL REPORT:

BARRIERS TO ACCESS TO HEALTHCARE FOR PEOPLE WITH DISABILITIES IN NEW MEXICO: TOWARDS IMPROVED PUBLIC HEALTH PRACTICE

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■ Institutional Review Board

This project, including project design, protocols and instruments used for the interviews and focus groups, was reviewed by the Human Research Review Committee (HRRC) of the Health Sciences Center of the University of New Mexico. The HRRC determined that the project is exempt from the requirements of Department of Health and Human Services (DHHS) regulations for the protection of human subjects.

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■ Introduction: Extending Our Concepts of “Access to Health Care”

Recent social models of disability view disability not as some failure or “problem” with an individual, but as the interaction between a particular individual’s capabilities and the characteristics of the physical, social and cultural environments with which he or she interacts.¹ Such a distinction places increased emphasis on the need to examine “access” as a broad concept, which includes but goes beyond a single focus on physical barriers.

In the area of health care, numerous studies have documented a wide range of physical, communicational and attitudinal barriers faced by people with physical and cognitive disabilities in accessing health care services.² Prior research has found that people with disabilities utilize health care services more frequently than people without disabilities³ and report dissatisfaction with health care more often than people without a disability.⁴

Numerous studies have documented the difficulties faced by people with disabilities in accessing health care services.

The Centers for Disease Control and Prevention (CDC) reports that only 48% of people with disabilities have access to local health facilities and wellness programs.⁵ Numerous studies show that people with disabilities are less likely to receive preventative health services and health promotion efforts than people without disabilities. Reasons for this disparity may be explained by healthcare providers’ self-reported difficulty in treating patients with disabilities and negative attitudes towards people with disabilities.⁶ Furthermore, evidence shows that physicians’ perceptions and assessments of disability are often significantly different from the perceptions of those with disabilities themselves.⁷

To investigate these issues in New Mexico, a project was developed with support from a multi-year disability and health grant program from the Centers for Disease Control and Prevention that sought to provide answers to four major questions:

- Do people with disabilities in New Mexico view access to health care as more of a problem than people without?
- What issues did people with disabilities see as major problems within the broad concept of “access”, including physical, social, communication and cultural issues?
- Did the perceptions of health care providers and people with disabilities differ regarding access to health care?
- What recommendations did people with disabilities have to improve their access to health care?

In designing project activities, CDD project research staff utilized the network of long-term strategic alliances with numerous New Mexican disability organizations that have been built over several years. This highly collaborative process included a statewide forum on access to health care attended by representatives of major disability organizations in the state, staff of public health offices and payer organizations including managed care organizations and senior research and project staff of the Disability and Health Program at the Centers for Disease Control and Prevention.

(See Appendix A for a list of attendees and Appendix B for a copy of the agenda). The forum resulted in a significant shift in planned project activities. Originally designed as a study focusing solely on physical access to health care facilities, participants at the forum suggested that the research team broaden the study to include other types of barriers, including communicational and attitudinal barriers.

Project staff used a multiple-methods approach in designing and carrying out the research project.

The process used to design the project was a highly collaborative one that involved a state-wide forum on access to health care for people with disabilities, resulting in a significant shift in project design.

- ***Population-Based Surveillance Research:*** in collaboration with researchers from the Centers for Disease Control and Prevention and the Epidemiology & Response Division of the New Mexico Department of Health, a series of questions on access to health care were included in the 2005 New Mexico Behavioral Risk Factor Surveillance System (BRFSS).
- ***Perceptions of Health Care Providers:*** eight New Mexico health care providers were interviewed in four cities around the state.
- ***Perceptions of People with Disabilities:*** In cooperation with several disability organizations in the state, six focus groups were held with people with multiple types of disabilities.

The remainder of this report contains a brief description of the methods used for each of these three project components and summarizes key findings. Finally, recommended strategies developed to address the gaps identified in this report will be presented. Recommendations are based upon feedback from a second forum on access to healthcare for people with disabilities held in April, 2007. Four criteria guided the development of the recommendations:

- **Feasibility:** whether the strategy can reasonably be developed and implemented using available resources (e.g., reforming the Medicare system to improve payments is not feasible within available resources);
- **Timeliness:** whether the strategy can be developed and implemented within a reasonable period of time;
- **Usefulness:** the extent to which the strategy is likely to have an impact on identified barriers; and
- **Replicability:** the extent to which the strategy can be replicated in New Mexico and elsewhere without additional significant resources.

■ Barriers to Access Reported By People with Disabilities: Findings from a Statewide Survey

Methods

Project staff collaborated with the Centers for Disease Control and Prevention (CDC) to add a series of questions on access to health care in the 2005 Behavioral Risk Factor Surveillance System (BRFSS) in New Mexico. The BRFSS is a national survey conducted each year in every state that collects information on health conditions in the adult population. Funded and coordinated by the CDC, the BRFSS surveys adults eighteen years of age and older who live in a private household and have a telephone. Because of the rigorous sampling and statistical analyses used in the BRFSS, it is one of the few statistically reliable surveys that can be used to generalize to the adult population of the state.

Respondents to the survey are divided into two groups - those reporting a disability and those not - through the use of two screening questions:

- *Are you limited in any way in any activities because of physical, mental or emotional problems?*
- *Do you now have any health problem that requires you to use special equipment such as a cane, a wheelchair, a special bed, or a special telephone?*

Respondents who answered “yes” to either of these questions were considered to have a disability. Respondents who reported having a disability using this definition were further divided into two groups:

- Disability not requiring assistance (answered yes to the first question and no to the second)
- Disability requiring assistance (answered yes to both questions)

Barriers to access to health care were investigated through this question, asked of all respondents (those reporting a disability and those not):

How much of a problem are the following four items in getting access to healthcare, defined as “...examinations, procedures and medical tests conducted by a doctor, nurse or other health professional”:

1. *Transportation*
2. *Distance from your home to the provider’s office*
3. *Design of the health care provider’s office*
4. *Attitude of the medical and support staff*

Data from the survey were analyzed to determine whether answers differed between people who reported having a disability as opposed to those who did not. Appropriate tests of statistical significance were applied to determine the probability that any differences in responses between these two groups was due to chance, or was in fact a “real” difference.¹

Findings

A total of 5,494 respondents completed the survey, and 19.5% of these respondents reported having a disability. There was a statistically significant difference in responses to accessing health care facilities based on disability status. In every case, a greater percentage of people with disabilities, particularly those requiring assistance, responded that they sometimes or always had a problem getting access to health care compared to people with no disability. Figures One through Four show the proportions of people responding that each of the access issues is sometimes or always a problem.

- **Transportation:** as Figure One shows, while only 4.2% of people without a disability said that transportation was sometimes or always a problem, over 7% of people with a disability not requiring assistance said it was, and nearly a third (32.4%) of people who have a disability requiring assistance said transportation was sometimes or always a problem.
- **Distance:** Figure Two indicates the percentage of respondents answering that distance is sometimes or always a problem in getting access to health care. Over a third (34.4%) of New Mexicans who have a disability requiring assistance report that distance from the provider’s office was sometimes or always a problem in accessing health care, compared to 6.9% of New Mexicans without a disability.
- **Physical Design:** Figure Three shows the proportions of respondents answering that the physical design of the office is sometimes or always a problem in getting access to health care by disability status. Only 3.7% of respondents without a disability said that design was sometimes or always a problem compared to 8.5% of respondents with a disability not requiring assistance, and 28.6% of respondents with a disability requiring assistance.
- **Attitude of Staff:** Figure Four shows the proportions of respondents answering that the attitude of staff in providers’ offices is sometimes or always a problem in getting access to health care by disability status. 13.7% of respondents without a disability said that attitude was sometimes or always a problem compared to 16.3% of respondents with a disability not requiring assistance, and 24.8% of respondents with a disability requiring assistance.

In every case, a greater percentage of people with disabilities, particularly those requiring assistance, responded that they sometimes or always had a problem getting access to healthcare compared to people with no disability.

¹ This was accomplished through a series of crosstabs, crossing disability status with each of the four access questions. The crosstabs generated a chi-square test which was used to check for significance between disability groups. P-values less than 0.05 were considered significant. This means that there is a less than 5% probability that the differences were due to chance.

Figure One
Percentage of New Mexicans Who Say That Transportation Is Sometimes Or Always A Problem In Getting Access To Health Care

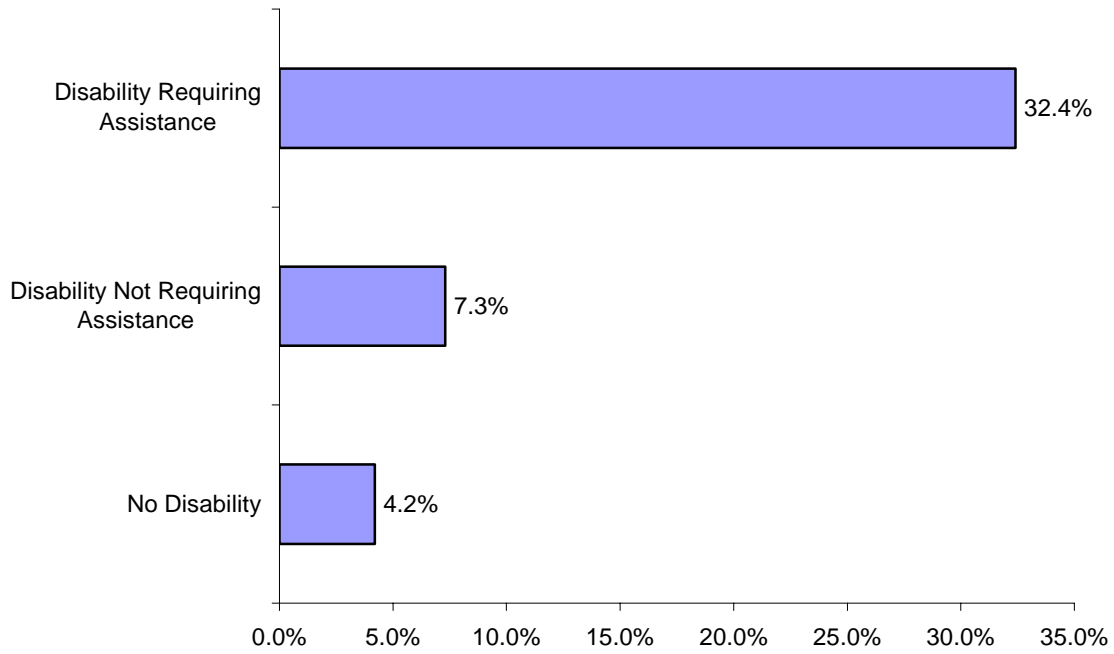


Figure Two
Percentage of New Mexicans Who Report That Distance From The Provider's Office Is Sometimes Or Always A Problem In Getting Access To Health Care

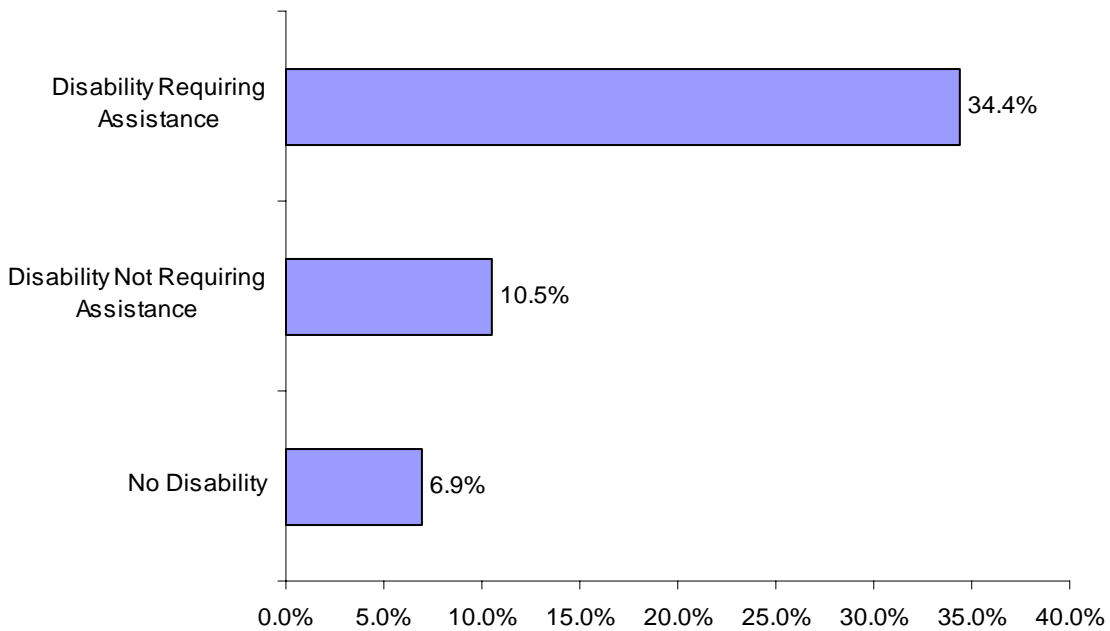


Figure Three
Percentage of New Mexicans Who Report That The Physical Design of The Provider's Office Is A Problem In Accessing Health Care

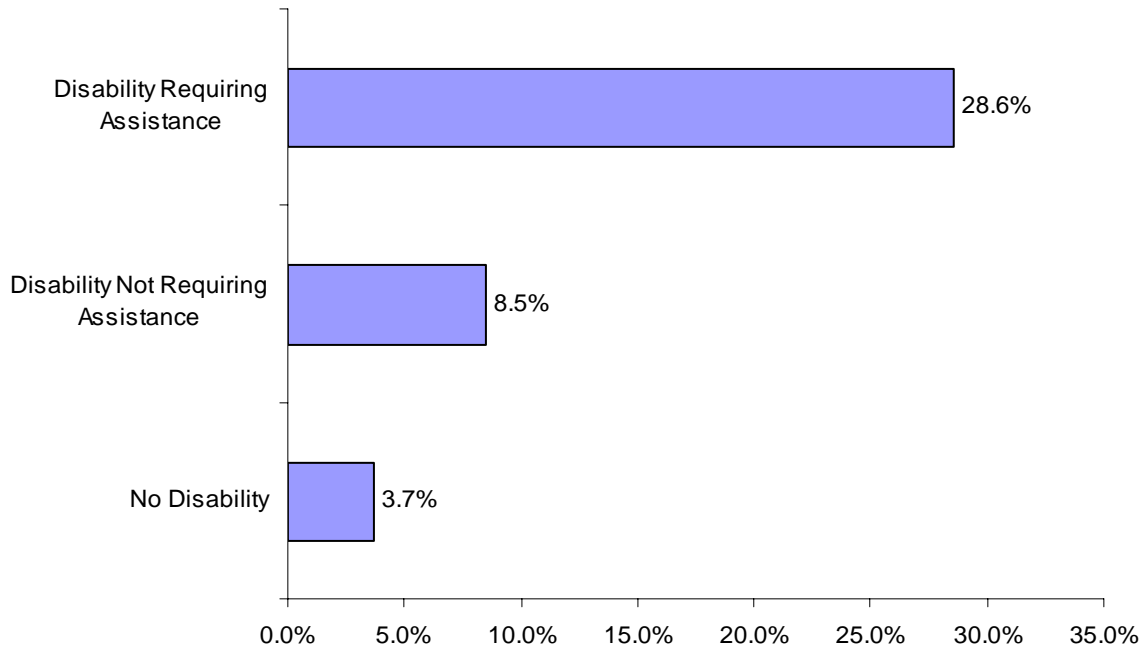
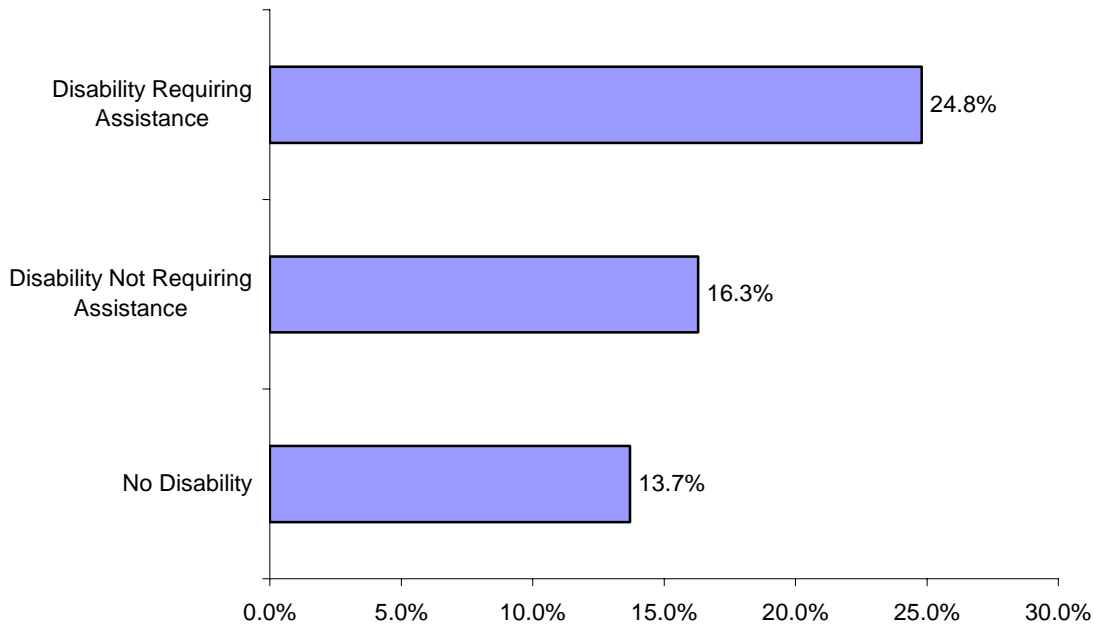


Figure Four
Percentage of New Mexicans Who Report that Attitude of Staff in Providers' Offices is a Problem in Accessing Health Care



■ Barriers to Access by People with Disabilities: Perceptions of Health Care Providers

Methods

Eight New Mexico health care providers were interviewed in four cities around the state including Albuquerque, Roswell, Las Cruces and Espanola.² The interviews were designed to gather information on:

- Providers' experiences with people with disabilities;
- Providers' views on major issues or problems they face when serving people with disabilities;
- Providers' perceptions on the barriers people with disabilities encounter when accessing health care at their facilities;
- The services and accommodations they offered at their offices; and
- Suggestions to improve services to people with disabilities.

Findings

In general, providers' perceptions of the barriers people with disabilities encounter when accessing care were limited to physical access and language barriers, and providers generally believed these barriers to be only minor problems. Of the eight providers interviewed, there was only one person who had extensive experience in serving people with disabilities, which was evident in her broad perceptions of disability and her identification of the extensive range of access barriers encountered by people with disabilities.

Of the eight health care providers interviewed, half perceived "only a handful" of their patients as having disabilities, and felt that serving people with disabilities was not a problem. However, one receptionist expressed some frustration because "they [people with disabilities] are used to getting their own way." A nurse practitioner also mentioned that it was sometimes difficult treating walk-in patients who often did not have a medical file on record, yet had complex medical histories that are often associated with disability.

Of the health care providers who perceived *many* of their clients as having a disability, their perceptions of disability were more inclusive of populations such as the elderly, patients with diabetes, people who were obese and overweight, people with mental health conditions, patients who were illiterate and people with mild-to-severe hearing and visual impairments. One healthcare provider also mentioned the challenges faced by people with "hidden disabilities" with relation to accessing appropriate care. The majority of providers said that people with disabilities do not need more appointment time than people with no disabilities, but as with all patients, are given as much time with a provider as needed.

² See Appendix C for a copy of the interview instrument.

Barriers to Physical Access

Most providers believed their facility was accessible to people with a wide range of disabilities in terms of physical characteristics of the building. However, front desk/ administration staff in some of the same facilities disagreed. At one public health facility, a receptionist identified a number of physical access barriers -- items that a physician from the same facility perceived as being "accessible". Providers at one primary care office mentioned the impossibility of weighing patients who were too heavy for the scale, and the difficulty in fitting a blood pressure cuff around the arm of an obese patient. The standard weighing scales also presented a problem for providers who needed to weigh patients in wheelchairs.

Communicational Access Barriers

The use of certified American Sign Language (ASL) interpreters by interviewees was mostly unheard of. One physician said that in the 17 months that he had been an employee at the public health office, there was only one occasion that a patient required a sign language interpreter. The physician relied on another staff member to help facilitate the interaction between himself and the patient. A number of providers perceived no problems with deaf or hearing-impaired patients relying on friends or family members to assist in the communication between patient and provider. One provider, however, expressed her concern about patient confidentiality when a third person is involved in the patient-provider interaction. Providing ASL interpreters for deaf patients did not seem to be a realistic possibility, especially for providers in rural areas of New Mexico.

The use of certified American Sign Language (ASL) interpreters at primary and public healthcare offices was mostly unheard of. Providing ASL interpreters for deaf patients did not seem to be a realistic possibility, especially for providers in rural areas of New Mexico.

Employees at two health care facilities said that they had a TTY service at the facility; however, employees at only one of the facilities knew how to operate it. Other perceived barriers to accessing healthcare from the perspective of providers included language barriers between providers and diverse patient populations.

With regard to informational materials for patients, most providers agreed that there was no market for materials in Braille. However, materials in large print might be useful for elderly patients and people with visual impairments. Most providers recognized a need for materials in Spanish but were unaware of materials in alternate formats specifically designed for people who are deaf or with cognitive disabilities. Some providers also prepared medication instructions in large print format for elderly patients with visual impairments.

■ Barriers to Access by People with Disabilities: Perceptions of People with Disabilities

Methods

In cooperation with several disability organizations in the state, six focus groups were held comprising people with five disabilities: people who are deaf or hard of hearing; people who are blind or visually impaired; people with mobility limitations; people with cognitive disabilities; and people with multiple chemical sensitivities. A sixth focus group was held with caregivers of people with cognitive disabilities. These focus groups were distinguished by type of disability in an effort to understand the unique challenges associated with different disabilities when accessing health care. Disability organizations assisting the research team assisted in recruiting participants through e-mail list-serves, flyers, and word-of-mouth.

Questions for each focus group instrument were reviewed by representatives from each participating organization prior to the focus groups. Focus group questions were added or modified to reflect the disability represented in each focus group. For example, questions about sign language interpreters were asked only in the focus group of deaf and hard of hearing persons. Common key questions were asked of all focus group participants pertaining to key topics such as:

- Challenges when accessing health care;
- Barriers to accessing health care;
- Positive and negative experiences when accessing healthcare;
- Experiences with health care provider staff;
- Experiences in accessing materials in alternate formats; and
- Means of accessing health information;

See Appendix D for a copy of the focus group instruments.

Findings

Participant Demographics

Forty one individuals participated in the six focus groups. Participants were mostly female, white and had an income of less than \$35,000/ year. Participant demographics are outlined below:

- 66% female
- 51% were college educated
- 20% Hispanic, 73% White
- 37% had an income of < \$10,000/yr
- 81% had an income of < \$35,000/yr

Common Issues: The Patient - Provider Relationship

Taken together, the most common barriers identified by participants in all focus groups were centered on the patient-provider interaction. In general, focus group participants expressed a willingness to drive long distances, arrange transportation or maneuver poorly designed waiting rooms for the opportunity to be seen by a health care provider who understands their disability and takes the time to tailor treatment to their specific needs.

Participants expressed their greatest dissatisfaction concerning providers who did not understand their disability. Of the 43 responses to the question that asked respondents to identify their biggest barrier to accessing health care:

- 67% related to the doctor-patient relationship (i.e. perceived communication challenges, lack of respect, lack of knowledge and understanding of disability; appointment and wait time issues);
- 31% related to individual circumstances (i.e. transportation; finances; insurance limitations; lack of post surgery support or attendant care); and
- 2% related to environmental challenges (e.g., parking problems).

Barriers to Accessing Healthcare for People who are Deaf or Hard of Hearing

Barriers to accessing health care for the deaf and hard-of-hearing were primarily related to communication issues. Focus group participants shared many stories about their health care experiences that left them frightened or confused. For the most part, situations that left the patient unable to communicate with their provider could have been avoided if a qualified interpreter was present.

“When I was in labor the interpreter was on a break. There was all this yelling and screaming and everything was taking place and I wanted the interpreter. It was terrible.”

“The doctor was going to put a tube down the deaf patient’s throat. The doctor didn’t explain the procedure, but it took place anyway. The patient didn’t know why there was a tube down his throat.”

Participants also discussed what they perceived as an inability of providers to recognize the necessity for a medically qualified interpreter, often relying on family members or other staff members who claim to know ASL to help facilitate communication between themselves and the provider.

“It’s like when someone on staff says they can sign, but they finger sign. I can’t understand them.”

Providers’ perceptions of barriers faced by people with disabilities were generally limited to physical access issues. One receptionist expressed some frustration when serving people with disabilities because “they are used to getting their own way.”

Of all the barriers people with disabilities face when accessing health care, the most common barriers identified centered on the patient-provider interaction. Of the 43 responses to the question that asked respondents to identify their biggest barrier to accessing health care, 67% related to the doctor-patient relationship.

“I went to the hospital and they knew I needed an interpreter. They said “What about the nurse’s daughter?” I asked the nurse whether she was certified and she said “No”. I had to become mean and fight and said I want a certified interpreter right now. It was scary to me and I didn’t like it. The doctor became awkward or uncomfortable. He perceived me as “mean” and it made communication more difficult. They [providers] look at the interpreter as an enabler. It’s not their decision how I communicate.”

Oftentimes, providers’ lack of understanding about hearing disabilities is cause for frustration for the patient. Negative attitudes about hearing impairments on the part of the provider, can often put the patient into a defensive position and ultimately lead to frustration for both provider and patient.

“I’m latent deaf. I can speak, so the doctors think I’m lying. I wait for hours in the waiting room because I can’t hear when they call my name. Some doctors are mean about it.”

“When I show up for an appointment, they ask, “Can you read lips?” I hate that question. It’s such a waste of time. They should know me better by now.”

Overwhelmingly, deaf and hard-of-hearing respondents were frustrated by what they perceived to be a constant battle to achieve their right to communicate with health care providers. They were frustrated by what they saw as a lack of respect from providers and their refusal to accommodate their communication needs.

“Hearing staff need to respect deaf patients as they do with other patients. They need to communicate with a patient when there is a decision to be made about a procedure that needs to be done. Many times deaf patients don’t know what is happening because the doctor made a decision without ever consulting the deaf patient.”

“The key to communication is respect. They may think I’m not very intelligent, because I’m deaf.”

Barriers to Accessing Healthcare for People who are Blind or Visually Impaired

Focus group participants who are blind and visually impaired also expressed their frustration about providers’ lack of understanding and questioning of their disability. Just as deaf participants had been asked, “Are you sure you can’t hear?” blind participants often felt discriminated against due to providers persistent questioning of their visual impairment

“They don’t know that we have special [assistive] equipment and so they always ask me “Are you sure you can’t see?”

“They don’t know that we have special [assistive] equipment and so they always ask me “Are you sure you can’t see?”

“At the doctors’ [office] there are support staff that say, “Are you sure you are blind?” I’ve been told that I don’t look blind... And I say, well I don’t know what that looks like – I’m blind.”

For blind and visually impaired respondents, barriers to accessing health care do not end with the provider, as environmental issues such as transport, facility layout and signage, and written treatment instructions were often reported as major impediments to accessing care. In terms of transport, participants usually relied on a family member or friend to transport them to their appointments, or make arrangements with their local para-transport service. When participants needed urgent medical care, or when their appointments ran over time or were late, they faced problems in getting themselves to and from their healthcare facilities.

“The hardest thing is if you take the paratransit– you have to wait five minutes to two hours. You don’t know how long it will take at the doctors’. And Paratransit is closed over Thanksgiving – what if it is an emergency? You also have to call seven days ahead.”

The readability of signs at healthcare facilities was also cause for concern for many of the focus group participants.

“I try to read Braille but sometimes the Braille isn’t properly done.”

“I find signs in Braille upside down.”

Blind participants also expressed their frustration with health care staff members who don’t understand how to accommodate the needs of the blind.

“There have been several occasions where the staff have taken the cane and pulled me along. I told them this is not how you use the white cane.”

“They turn into a room so fast that you don’t know where they went. They need to pay more attention if you are following them. There may be things in the aisle that get in the way. There are narrow halls that we need some guidance with.”

Barriers to Accessing Health Care for People with Cognitive Disabilities and Caregivers

People with cognitive disabilities also identified barriers to accessing health care specifically related to the patient-provider relationship. Focus group participants said that physicians often talked too fast or used complex language that was confusing and difficult to understand.

“I felt confused because the doctor didn’t explain things well.”

“Many times the doctor’s staff talk too fast or use big words.”

Participants with cognitive disabilities also expressed how the long wait-times in waiting rooms can be difficult and frustrating.

“The waiting is the biggest problem and the doctors don’t spend enough time with me.”

Caregivers of people with cognitive disabilities who took part in a focus group of their own reinforced the barriers iterated by people with cognitive disabilities especially related to the patient-provider relationship, including physicians’ difficulties in communicating directly with the patient.

Caregivers said that oftentimes, physicians will direct their questions and instructions to the caregiver, rather than the patients themselves, denying the patient any chance to ask and answer questions or communicate their concerns.

“At least 80% of time, the doctor will talk to the caregiver rather than the patient.”

“At least 80% of time, the doctor will talk to the provider rather than the patient.”

“Even with verbal prompts, providers will still direct their conversation to us rather than the patient.”

Caregivers also expressed their concern over providers' lack of documentation or follow-up with the patient and how little they seem to know about their patient's medical history prior to the appointment. Caregivers were also concerned about providers' lack of understanding about their patients and how treatment, or lack thereof, affects their quality of life.

“Providers need to understand that people with disabilities have a quality of life, and the provider needs to do what he/she can to ensure that a person's quality of life is achieved. Providers need to find out who that person is and what he/she needs.”

Caregivers expressed their concern for how the time spent in the waiting room at a primary care office can affect the care the patient receives, and felt that this aspect of the visit is often overlooked by providers.

“You could be waiting at least two hours before the provider sees the patient. It makes it difficult for the patient who may have anxiety issues. We need books, snacks, games and things to occupy the patient. The patient's care is then affected.”

“The long wait time reflects on the type of care that they receive. There should be some type of accommodation for people with high levels of anxiety.”

Finally, caregivers felt that physicians often undermined their role, preventing them from ensuring that their clients' best interests are met.

“The primary care physician knew my client, and when I attempted to explain my role in the appointment, the physician said – “I won't remember this – it's not valid.” He did not understand my role in the client's care.”

Caregivers felt that physicians often undermined their role, preventing them from ensuring that their clients' best interests are met.

“I had a client that has Pica. I explained to the providers that the client needs a sitter. As the provider discounted what I told him, the client swallowed an instrument.”

Barriers to Accessing Health Care for People with Multiple Chemical Sensitivities

People with multiple chemical sensitivities (MCS) also identified providers' lack of understanding as a primary barrier to accessing health care. Members of the MCS focus group felt that many providers were even unwilling to recognize MCS as a legitimate medical condition, meaning that they were often turned away from treatment and testing. Furthermore, MCS participants were particularly troubled by the way in which providers continually questioned their condition, consequently leading them to delay seeking treatment.

People with multiple chemical sensitivities (MCS) also identified providers' lack of understanding as a barrier to accessing healthcare.

"I was referred to a physician who was able to see me, but it was a very invalidating experience. This doctor was very dismissive. I told him that I have MCS and Chronic Fatigue... and he interrupted me and said, "That's not a real diagnosis, you know."

"I noticed that doctors are just ignorant. They don't own that they are ignorant and don't take responsibility about their ignorance. They then project it on the patient. I don't know what to do. They want to blame the patient."

Financial issues were also identified as a major barrier to accessing health care for the MCS group.

"I'm on Medicare so I don't get the benefit of homeopathy. Being on disability, I find it hard to pay for more."

"Sometimes I'm so sick I can't even go out of the house. I'm just making it on disability. Fewer doctors are taking Medicare. The few doctors that I'd really like to go see, I can't, because I can't afford it. It's very stressful, and stress aggravates my condition even more."

Finally, MCS participants perceived indoor environmental conditions at healthcare facilities as not only a barrier to accessing health care, but as being more damaging to their health than if they did not access care in the first place.

"I was hospitalized for four days for a life-threatening asthma attack. Everything was done right, except the respiratory therapist came in wearing perfume."

"I went to an office where there were a bunch of nurses. They sprayed so much air freshener in the bathroom that it made me sick. I would hold my breath and quickly go in and out."

"It seems like all doctor's offices use industrial strength cleaners."

Barriers to Accessing Healthcare for People with Mobility Limitations

For people with mobility limitations, the greatest barriers to accessing health care were related to the patient-provider relationship and physical access issues. Barriers identified by participants included inaccessible parking, stressful and uncomfortable waiting rooms, maneuvering heavy doors and difficulties with carpeting. Numerous participants in wheelchairs or with back injuries, also said that long wait-times caused them discomfort and pain.

“The doors are hard to get open and the bathroom doors are too heavy.”

“They act like we chose to grow up and be disabled. This is life, this is what we have to live with.”

“You park in the middle of the waiting room. You might have someone with a little sense and they help pull a chair so I have some space. The shrieking kids hurt my head and it’s a long wait even if you have an appointment.”

“We just want to be treated like a person, be treated like everyone else, be treated well.”

“The nurses referred to me as my disease. The bottom line is rudeness and ignorance of the disease.”

■ Recommendations to Improve Public Health Practice in Access to Health Care for People With Disabilities

The first statewide forum on access to health care for people with disabilities was the catalyst for the research on which this report is based. A second statewide forum was convened in April, 2007 to discuss strategies that address the gaps identified in this report. Participants were asked to offer recommendations based upon four criteria:

- **Feasibility:** whether the strategy can reasonably be developed and implemented within available resources (e.g., reforming the Medicare system to improve payments is not feasible within available resources);
- **Timeliness:** whether the strategy can reasonably be developed and implemented within a reasonable period of time;
- **Usefulness:** the extent to which the strategy is likely to have an impact on identified barriers; and
- **Replicability:** the extent to which the strategy can be replicated in New Mexico and elsewhere without additional significant resources.

Based on study findings and feedback from participants at the second statewide forum, it is clear that strategies targeted at increasing access to health care for people with disabilities should achieve two objectives: to increase provider awareness about disability-related issues affecting access to health care by people with disabilities and to facilitate the empowerment of people with disabilities to access healthcare effectively and to their satisfaction.

To achieve the above objectives, the following strategies are recommended:

1. **Develop and make available a centralized resource compendium comprised of educational materials about access and disability**

Health care providers could provide improved services to people with disabilities if they had ready access to existing resources and materials, including posters for health care facility waiting rooms and offices, provider training resources with attached CEU's/ CME's, pamphlets, brochures, letters, tool-kits or on-line resources designed to increase access to health care for people with disabilities. These and other types of materials exist, but are not readily available to providers. These materials should be identified, assessed for their appropriateness and gathered into a centralized resource system that can be accessed by health care providers.

2. **Develop Access to Healthcare for People with Disabilities *Tip Sheets***

Tip Sheets were first developed by a consortium led by the University of New Mexico's Center for Development and Disability to educate emergency responders about the needs of people with a variety of disabilities in a public emergency or natural disaster. A *Tip Sheet* is much like a field guide that provides simple-to-follow tips on how to appropriately serve persons with spe-

cific disabilities in an emergency. Over 60,000 *Tip Sheets* have been distributed nationally to emergency responders throughout the United States.

Several primary care providers present at project briefings recommended that a similar *Tip Sheet* be developed to provide practical information on how to deal with barriers encountered by people with disabilities when accessing healthcare. *Tips for Providers on Accessible Healthcare* will offer information to providers about how to ensure appropriate access to healthcare for patients with disabilities. The guide will provide healthcare providers with practical (and inexpensive) tips on how to make their encounters with people with disabilities and their healthcare facilities, more accessible. A brief accompanying presentation will go with the *Tip Sheets* to allow providers to discuss the *Tips* and ask questions about its use.

3. Convene a meeting with New Mexico policy makers to 1) review current tax exemptions aimed at eliminating barriers to access at healthcare facilities, and b) establish measures to promote wide-spread use of current tax-based incentives by healthcare facilities in New Mexico

Feedback from the second access meeting revealed that existing state policy provides tax incentives to healthcare facilities to make modifications to improve access. It was suggested that there be an emphasis on promotion of policy-level and financial incentives to ensure barriers to access be eliminated or reduced. A meeting with state policy makers would be the first step in raising awareness about these policies.

4. Investigate whether a partnership could be developed with UNM Telehealth services to design a system that provides people who are deaf with ASL interpreter services when interacting with a healthcare provider through real-time television communication

This strategy specifically addresses providers' minimal use of American Sign Language interpreters when serving people who are deaf, especially in rural areas of the state. It was suggested that the Telehealth program at the University of New Mexico be utilized to bring together providers, patients and ASL interpreters (regardless of their geographical location), to ultimately facilitate an effective interaction between providers and deaf patients. The use of Telehealth and other new technologies is an area of intervention strongly advocated by the deaf community.

5. Connect consumers with existing educational programs

Feedback from the focus groups revealed that many individuals with disabilities advocate for themselves and are willing to help educate providers about disability access issues. It is recommended then that people with disabilities are assisted in their endeavor to access health care and receive health care that satisfactorily meets their needs. The Continuum of Care Project at the Center for Development and Disability assists people with disabilities in navigating the healthcare system and ensuring that their needs are met when they visit their primary care physician, a specialist or any other healthcare provider. Efforts to connect more people with disabilities to existing programs of this nature are recommended.

■ Appendices

**Appendix A:
Participants at Statewide Forum on Access to Health Care
for People with Disabilities**

Tom Dillon
New Mexico Commission for the Deaf

Linda Monk
New Mexico Department of Health, Public Health Division

Patsy Nelson
Deputy Director, New Mexico Department of Health, Public Health Division

Kristine Suozzi
Director, New Mexico Department of Health, Public Health Division

Ray Stewart
District Director, New Mexico Department of Health, Public Health Division

Mary Beresford
Director, New Mexico Governor's Commission on Disability

Christina Carrillo
Director, Office of Health Promotion and Community Health Improvement

Susan Gray
New Mexico Department of Health, Office of Disability and Health

Bil Schmidt
Director, Traumatic Brain Injury Program
New Mexico Aging and Long Term Services

Pat Larragoite
Director, New Mexico Health Policy Commission

Margy Weinbar
Presbyterian Health Plan

Joann Salazar
Chief, Health Systems Bureau

Tony Cahill
Director, University of New Mexico, Center for Development and Disability, Division of Disability and Health Policy

Judy Liddell
Associate Director, University of New Mexico, Center for Development and Disability

Greg Trapp
Director, New Mexico Commission for the Blind

Joie Glen
Director, New Mexico Association for Home Care

Nat Dean
Santa Fe Mayor's Committee on Concerns of People with Disabilities

Mary Helen Witten
Centers for Disease Control and Protection

Don Betts
Centers for Disease Control and Protection

JoAnn Thierry
Centers for Disease Control and Protection

Hope Reid
New Mexico Governor's Commission on Disability

Susan Gonzalez
New Mexico Primary Care Association

Ralph Vigil
Division of Vocational Rehabilitation

Chanai Adams
New Mexico Human Services Department

**Appendix B:
Agenda for 2005 Statewide Forum on Access to Health Care
For People with Disabilities**

**ACCESS TO HEALTH CARE IN NEW MEXICO FOR PEOPLE WITH DISABILITIES:
CURRENT STATUS AND FUTURE PLANS**

**Corrales Room, Amerisuites Hotel
2500 Menaul Boulevard NE**

-
- 8:30 AM - 9:00 AM** Continental Breakfast
- 9:00 AM - 9:15 AM** Welcome and Introductions
Joann Salazar, Chief, Health Systems Bureau, Public Health Division
- 9:15 AM - 10:00 AM** Access to Health Care for New Mexicans With Disabilities:
What Do The Data Show?

Dr. Anthony Cahill, Senior Research Scientist,
Center for Development and Disability
- 10:00 AM - 10:15 AM** Break
- 10:15 AM - 10:30 AM** Overview of Planned Activities to Assess Access in Public Health District
and Primary Care Offices

Susan Gray, Director, Office of Disability and Health
- 10:30 AM - 11:30 AM** Breakout Groups: What Are The Issues in Access to Health Care for New Mexicans
With Disabilities?

*Participants will divide up into breakout groups, each led by a facilitator, to discuss
their concerns and priorities regarding access to health care. A recorder will sum-
marize results of each session.*
- 11:30 AM - 11:45 AM** Break to get lunch from buffet table
- 11:45 AM - 12:45 PM** Wrap-Up: Summarizing Issues and Priorities

*Recorders from each of the breakout groups will report out results. These will be
used to compile a prioritized list of issues and concerns that will be used by project
staff to revise or adjust planned activities around access.*

**Appendix C:
State Added Module 3: Disability**

If Response to S17.1 or S17.2 in the core is 'Yes,' (1) continue.

Otherwise go to SAM 3.6, page 44

Earlier in the interview, you said you were limited in your activities/or you use special equipment because of a health problem or impairment. Next I have some additional questions about your limitation.

longlmtd

SAM3.1 For HOW LONG have your activities been limited because of your major impairment or health problem? (SA 360-362)

1 __ Days

2 __ Weeks

3__ Months

4__ Years

7 7 7 Don't know/Not sure

9 9 9 Refused

distanc2

SAM3.2 What is the farthest distance you can walk by yourself, without any special equipment or help from others? Would you say (SA 363)

1. Not any distance

2. Across a small room

3. About the length of a typical house

4. About one or two city blocks

5. About one mile

6. More than one mile

Do not read

7. Don't know/Not sure

9. Refused

qlpersnl

SAM3.3 Because of this limitation or health problem, do you need the help of other persons with your PERSONAL CARE needs, such as eating, bathing, dressing, or getting around the house? (SA 364)

1 Yes

2 No

7 Don't know/Not sure

9 Refused

qlroutin

SAM3.4 Because of this limitation or health problem, do you need the help of other persons in handling your ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes? (SA 365)

1 Yes

2 No

7 Don't know/Not sure

9 Refused

painactv

SAM3.5 During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such as self-care, work, or recreation?

(SA 366-367)

___ ___ Number of days

8 8 None

7 7 Don't know/Not sure

9 9 Refused

For the following questions, health care includes examinations, procedures, and medical tests conducted by a doctor, nurse or other health professional.

hctrans

SAM3.6 How often is transportation a problem for you in getting health care? Would you say..

(SA 368)

1 Not a problem

2 Rarely a problem

3 Sometimes a problem

4 Often or always a problem

Do not read

7 Don't know / Not sure

9 Refused

hcdist

SAM3.7 How often is distance a problem for you in getting from your home to your doctor's office?

Would you say . . . (SA 369)

1 Not a problem

2 Rarely a problem

3 Sometimes a problem

4 Often or always a problem

Do not read

7 Don't know / Not sure

9 Refused

hcdesign

SAM3.8 How often is the design of the health care provider's office a problem? For example, too many steps or difficulty in getting on the exam table. Would you say (SA 370)

1 Not a problem

2 Rarely a problem

3 Sometimes a problem

4 Often or always a problem

Do not read

7 Don't know / Not sure

9 Refused

hcexp

SAM3.9 How often do you experience an unfriendly or unhelpful attitude from the medical and support staff in your doctor's office? Would you say . . . (SA 371)

- 1 Not a problem
 - 2 Rarely a problem
 - 3 Sometimes a problem
 - 4 Often or always a problem
- Do not read
- 7 Don't know / Not sure
 - 9 Refused

The next two questions are about your support needs and life satisfaction.

support2

SAM3.10 How often would you say that you get the social and emotional support from family, friends, or community? Would you say

I support you need

(SA 372)

- 1. Always
- 2. Usually
- 3. Sometimes
- 4. Never

Do not read

- 7. Don't know/Not sure
- 9. Refused

satisfy

SAM3.11 In general, how satisfied are you with your life?

- 1. Very satisfied

Would you say

(SA 373)

- 2. Satisfied
- 3. Dissatisfied

Do not read

- 4. Very dissatisfied
- 7. Don't know/Not sure
- 9. Refused

Appendix D: Focus Group Instruments

Focus Group for Deaf and Hard of Hearing Persons

Questions

1. Please share some negative experiences that stand out in your mind, when you have visited a healthcare provider.

Probes:

- Think about the times when you have been made to feel
 - Uncomfortable
 - Embarrassed
 - Burdensome
 - Unsatisfied
 - Different
- Have there been times when you have left the healthcare clinic more worried about your medical issues than before your appointment? Explain.
- Have there been times when you have sworn never to go back to a particular healthcare provider? Explain.
- Have there been times when you have felt discriminated against because you have a hearing impairment? Explain.
- Do you feel rushed at your doctor's visit? How so?
- Have there been times when you have been confused about follow up treatments? Explain.
- Have there been times when you have sensed frustration from your physician or other staff members because they are not able to communicate with you effectively? Explain.
- Has your independence ever been compromised because of a shortfall in facilities or staff competencies? Explain.
- Have staff members acted in a patronizing way when explaining medication guidelines or follow up treatment?
- Have you ever undergone treatment or surgery without fully understanding its implications or giving your consent? Explain.
- Have you ever avoided seeking care because visiting your health clinic is too much trouble than it's worth? Explain.

2. Please share some of your more positive experiences when accessing healthcare.

Probes:

- Think about the times when you have left your visit, satisfied with the care you received. Explain.
 - Is there a health clinic that you would prefer to visit more than another? Explain.
 - Is there a particular physician you would prefer to see more than another? Explain.
3. What are some of the problems you have encountered with staff members when you visit your health clinic?

Follow On:

- Do you believe these problems are due to your hearing impairment?
 - What can staff members do to make your visit more enjoyable?
4. How important is it to you to have informational materials that you can understand?
 5. Would you be willing to pay more money if your physician:
 - Made home visits?
 - Could communicate to you in ASL?
 - Would provide an interpreter?
 6. In what circumstances would you be willing to drive long distances or be flexible with your schedule to have an appointment with practitioners who can:
 - Communicate in ASL?
 - Provide you with an interpreter?
 - Use TTY for scheduling appointments?
 7. How do you learn about different health issues, diseases, treatments, and preventative information?

Probes:

- Where do you get most of your health information? (Friends, family, the media, books, brochures, pamphlets, doctor) If the response is "friends and family," ASK:
 - Do these people also have hearing impairments? AND
 - Where do they get their information?
- When you visit your physician about a particular medical issue, do you rely on your physician to provide you with all the information you need to know?
- Do you feel comfortable asking your physician questions?

- Do you prefer to have a family member or friend with you when you visit your physician? Does this person have a hearing impairment also?
8. Think of the health clinic that you visit most often. Does the facility provide you with interpreter services? How does using interpreter services affect your visit?

Probes:

- Have there been times when you have been too embarrassed to discuss an issue with your physician because you have to communicate through an interpreter?
 - Have there been times when you have chosen not to discuss a particular issue with your physician because you are concerned that the interpreter might not keep it confidential?
 - Are you more or less anxious communicating with a physician through an interpreter?
9. Have you ever undergone treatment or surgery without fully understanding its implications or giving your consent? Do you attribute this to miscommunication between you and your physician? Explain.
10. Is it important to you to have the equipment you need at your health care clinic, such as a portable, amplified communication system or device or TTY to make phone calls? Explain.
11. If you were to name the biggest challenge when accessing health care, what would it be?

Focus Group For People Who Are Blind Or Visually Impaired

Questions

1. Please share some negative experiences that stand out in your mind, when you have visited a healthcare provider.

Probes:

- Think about the times when you have been made to feel
 - Uncomfortable
 - Embarrassed
 - Burdensome
 - Unsatisfied
 - Different
 - Frustrated
 - Have there been times when you have left the healthcare clinic more worried about your medical issues than before your appointment? Explain.
 - Have there been times when you have sworn never to go back to a particular healthcare provider? Explain.
 - Have there been times when you have felt discriminated against because you have a visual impairment? Explain.
 - Do you feel rushed at your doctor's visit? How so?
 - Have there been times when you have been confused about follow up treatments? Explain.
 - Have there been times when you have sensed frustration from your physician or other staff members because they are not able to explain things effectively? Explain.
 - Has your independence ever been compromised because of a shortfall in facilities or staff competencies? Explain.
 - Have staff members used patronizing language towards you when explaining medication guidelines or follow up treatment? Explain.
 - Have you ever undergone treatment or surgery without fully understanding its implications or giving your consent? Explain.
 - Have you ever avoided seeking care because visiting your health clinic is too much trouble than it's worth? Explain.
2. Please share some of your more positive experiences when accessing healthcare.

Probes:

- Think about the times when you have left your visit, satisfied with the care you received. Explain.

- Is there a health clinic that you would prefer to visit more than another? Explain.
 - Is there a particular physician you would prefer to see more than another? Explain.
3. What are some of the problems you have encountered with staff members when you visit your health clinic?

Follow On:

- Do you believe these problems are due to your visual impairment?
 - What can staff members do to make your visit more enjoyable?
4. How important is it to you to have informational materials available in Braille (e.g., information pamphlets/brochures)?
5. Would you be willing to pay more money if your physician made home visits? Explain.
6. How do you learn about different health issues, diseases, treatments, and preventative information?

Probes:

- Where do you get most of your health information? (Friends, family, the media, books, brochures, pamphlets, doctor) If the response is “friends and family,” ASK:
 - Do these people also have visual impairments? AND
 - Where do they get their information?
 - When you visit your physician about a particular medical issue, do you rely on your physician to provide you with all the information you need to know?
 - Do you feel comfortable asking your physician questions?
 - Do you prefer to have a family member or friend with you when you visit your physician? Does this person have a visual impairment also?
7. In what circumstances would you be willing to drive long distances or be flexible with your schedule to have an appointment with practitioners who accommodate your visual impairment?
8. Think of the health clinic that you visit most often:
- Do you find the facilities appropriate for you to navigate easily?
 - Is it easy for you to move freely throughout your facility?
 - Is it important to have directional signs in Braille?
9. Explain how transportation affects when and where you access health care.
10. If you were to name the biggest challenge when accessing health care, what would it be?

Focus Group with Caregivers of People with Disabilities

Questions

1. Please share some negative experiences that stand out in your mind, when you have accompanied a person with a developmental disability to a healthcare provider.

Probes:

- Think about the times when you or the person you are assisting have been made to feel
 - Uncomfortable
 - Embarrassed
 - Burdensome
 - Unsatisfied
 - Different
 - Frustrated
 - Have there been times when the person you are assisting has left the healthcare clinic more worried about his/her medical issues than before the appointment? Explain.
 - Have there been times when you have sworn never to go back to a particular healthcare provider? Explain.
 - When you take a person with a disability to a healthcare provider, do you feel rushed? How so?
 - Have there been times when you have been confused about how to assist someone with their follow up treatments or medications? Explain.
 - Have there been times when a doctor or nurse, or other healthcare provider directs their attention, questions or conversation to you, rather than the patient? Explain
 - Have staff members acted in a patronizing way when explaining medication guidelines or follow up treatment to you or the person you are assisting?
2. Please share some of your more positive experiences when you accompany a person to a healthcare provider.

Probes:

- Think about the times when you have left your visit, satisfied with the care your patient received. Explain.
- Is there a health clinic or physician that you prefer people with disabilities visit more than another? Explain.

3. What are some of the problems you have encountered with staff members at the doctor's office when accompanying a person with disabilities to visit their healthcare provider?

Follow On:

- Why do you think these problems occur?
 - What can staff members at the doc's office do to make the people with disabilities' visits more beneficial/enjoyable?
4. Do you think that it would be more beneficial for people with disabilities to have their physician visit them at their home? Explain.
 5. How do the people you care for learn about different health issues, diseases, treatments, and preventative information?

Probes:

- Where do they get most of their health information? (Friends, family, the media, books, brochures, pamphlets, doctor)
 - From your perspective, do you believe that the person you are assisting feels comfortable asking his/her physician questions?
6. Think of the health clinics that you and the people you are assisting visit most often.
 - Do you find the facilities appropriate for people with disabilities to navigate easily?
 - Are there accessible bathrooms?
 - Is the waiting room a comfortable area for patients?
 - Is it easy for people with disabilities to move freely throughout the facility?
 7. Do you know of times when people with disabilities have undergone treatment or surgery without fully understanding its implications or giving their consent?
 8. If you were to name the biggest challenge when people with disabilities are accessing health care what would it be?

Focus Group With People With Cognitive Disabilities

Questions

11. Please share some bad experiences that stand out in your mind, when you have visited a healthcare provider.

Probes:

- Think about the times when you have been made to feel
 - Uncomfortable
 - Embarrassed
 - Burdensome
 - Unsatisfied
 - Different
 - Frustrated
- Have there been times when you have left the doctor's office more worried about how you are feeling than before your appointment? Explain.
- Have there been times when you have said that you would never go back to a doctor? Explain.
- Have there been times when you have not been treated fairly because you have a cognitive disability? Explain.
- Do you feel rushed at your doctor's visit? How so?
- Have there been times when you have been confused about what to do next? Explain.
- Have there been times when you get mad at your doctor or the doctor's staff members because they are not able to explain things so you can understand? Explain
- Have there been times when doctors or nurses talk too fast or use big words that you don't know?
- Have there been times when doctors are not open for your questions?
- Have there been times when your doctor or nurse used words that made you feel small?
- Have you ever had treatment or surgery without knowing how it was going to affect you life? Explain.
- Have you ever avoided seeing your doctor because visiting him/her is too much trouble than it's worth? Explain.

12. Please share some good experiences when accessing healthcare.

Probes:

- Think about the times when you have left your doctor, happy with the care you received. Explain.
- Is there a doctor's office that you would prefer to visit more than another? Explain.
- Is there a particular doctor you would prefer to see more than another? Explain.

13. What are some of the problems you have encountered with people at the doctor's office?

Follow On:

- Do you believe these problems are due to your cognitive disability?
- What can staff at the doctor's office do to make your visit better?

14. How important is it to you to have flyers that are written in ways you can understand?

15. Would you be willing to pay more money if your doctor made home visits? Explain.

16. How do you learn about different health issues, diseases, treatments, and preventative information?

Probes:

- Where do you get most of your health information? (Your staff, friends, family, the media, books, flyers, pamphlets, doctor, internet, Medline) If the response is "friends and family," ASK:
 - Do these people also have cognitive disabilities? AND
 - Where do they get their information?
- When you visit your doctor about your medical problem, do you rely on your physician to provide you with all the information you need to know?
- Do you feel comfortable asking your doctor questions?
- Who do you prefer to have with you when you visit your doctor? Does this person have a cognitive disability also?
- How well do you know the direct support staff that goes with you to see the doctor?
- Would you prefer to go to the doctor with someone you know well, or someone that you don't know?

17. Think of the doctor's office that you visit most often:

- Do you find the building easy for you to use?
- Are there signs you can follow to get where you need to go?

18. Explain how getting a ride affects when and where you visit the doctor?

19. If you were to name the biggest problem about going to the doctor's office, what would it be?

20. Do you have any other problems about visiting your doctor that you want to speak about?

Focus Group For People With Medical Chemical Sensitivities

Questions

1. Please share some negative experiences that stand out in your mind, when you have visited a healthcare provider (which may include a health care provider, such as a physician).
2. Please share some of your more positive experiences when accessing healthcare. (*Ask: "Who would like to start?" Then, go to the next person on the right until you get back to the person who started*)
3. Have there been times when you have chosen not to discuss a particular issue with your physician because you were concerned that the physician would not believe you, understand it, or keep it confidential?
4. Would you be willing to pay more money (and/or drive long distances) if your physician:
 - Made home visits?
 - Understood how to accurately diagnose and treat MCS?
5. How do you learn about different health issues, diseases, treatments, and preventative information?
6. Think of the health clinic or hospital you have visited that had poor indoor air quality that affected your condition.
7. Have you ever undergone treatment or surgery without fully understanding its implications or giving your consent? Do you attribute this to miscommunication between you and your physician? Explain.
8. How have financial and insurance barriers played a role in being effectively diagnosed and treated with MCS? Explain.
9. LAST QUESTION: If you were to name the biggest challenge when accessing health care? Would you say this is the biggest change that needs to be made?

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