Health Care Access Survey

By DeAnn Elliott

Prepared on behalf of the Bay State Council of the Blind
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Introduction

In the spring of 2015, Commissioner Paul Saner of the Massachusetts Commission for the Blind (MCB) asked the Bay State Council of the Blind (BSCB) to provide feedback from members about their experiences accessing health care in the Commonwealth. The Commissioner’s request was prompted by a request for information from State Senator Michael Barrett (D Lexington) who was concerned that Massachusetts residents with disabilities were not receiving the same quality of health care as people without disabilities. The senator introduced a bill (S. 565) to create an Office of Health Equity that would establish goals, recommend policies, and work with other agencies to reduce the differences that are often experienced by patients due to disability, race, and ethnicity.

The BSCB is the Massachusetts affiliate of the American Council of the Blind, one of the two largest blind consumer advocacy organizations in the United States. Working in partnership with the Massachusetts chapter of the National Federation of the Blind (NFB,) the other leading blind advocacy organization, a 16-item questionnaire was developed for email distribution to both groups (see attached.) The focus of the survey was limited to disparities in health care access (transportation, communication, affordability of treatment, and skill of provider in working with disability) rather than health disparities (the incidence, prevalence, mortality and burden of diseases.)

The BSCB sent 258 questionnaires to people on the BSCB mailing list. This number included members, blind non-members, and a limited number of sighted supporters. The BSCB received 20 completed questionnaires, for a response rate of 8%. All respondents indicated that they had a visual disability.

This report provides a summary and analysis of the BSCB responses, including a list of narrative comments that participants submitted in response to open-ended questions. Given the email format of the survey, respondents were asked not to include highly personal information, as it was not possible to guarantee confidentiality. To protect participant privacy, all names and identifying information have been removed.

It should be noted that advocacy organizations such as the BSCB and NFB represent the interests of the blind community, but are not representative of it. According to the MCB, there are approximately 30,000 legally blind citizens in the commonwealth. The overwhelming majority of blind individuals do not join advocacy organizations. The sample size is small and the survey does not attempt to be scientific.
Additionally, blind individuals who are active in advocacy organizations are probably more likely than non-members to have a college degree, be employed, and live in metropolitan areas, where there is a wider range of transportation options and greater access to quality health care. While there are many high-functioning blind citizens who choose to be non-political, those who join advocacy groups are generally strong self-advocates. It is also possible that people with negative experiences are more likely to complete a questionnaire. The strength of the sample is that issues which affect the respondents of this survey probably have an even greater impact on blind citizens who are less outspoken and less connected to the blindness community.

**Demographic Profile of Respondents**

Of the 20 responses, 13 (65%) were female and 7 (35%) were male. Eight (40%) indicated that their blindness was total, 8 (40%) said they had very limited vision, and 4 (20%) had some usable eyesight. The largest number of responses came from the 55 to 64 age group (9, or 45%). Seven (35%) were in the 45 to 54 age group. Two respondents (10%) were aged 35 to 44, and 2 (10%) were older than 65. There were no responses from people under 35. Since blindness is correlated with age, and many legally blind individuals have some remaining vision, the demographic profile of respondents mirrors BSCB membership.

**Analysis of Results**

When asked if they had ever chosen a doctor because his or her office was easy to get to when they would have preferred to see a different doctor if they had had other transportation options, the majority (60%) said yes. A number of respondents listed transportation as one of the three greatest barriers in obtaining health care (see attached narrative notes.) Thirteen (65%) of respondents reported that they had not postponed medical treatment (including filling prescriptions and dental care) due to financial concerns. While this figure represents a majority, it is worth noting that 35%, or one-third, indicated that medical costs had been a barrier. Since health insurance is often linked to employment, and the unemployment rate for blind individuals is high, the results are not surprising. Respondents with financial barriers were not clustered by gender, age, or degree of vision loss.

When asked if they had had a medical professional explain something to them with visual aids (graphs, photos, or models) that left them feeling they understood the information less well than if another communication technique had been used, slightly more than half (55%) said yes. The figure is important because patients who are knowledgeable about their health issues are better equipped to manage their own medical care and to be effective self-advocates. Given that Massachusetts has some of the finest medical institutions in the country, the responses suggest that the medical community could do more to find creative, non-traditional ways to give medical information to patients with visual disabilities.

Two-thirds of respondents (13, or 65%) indicated that they had a medical condition such as hypertension or diabetes that required them to take measurements. When asked if the professionals who worked with them were aware of and able to provide guidance around obtaining and using adaptive devices, 8 of the 13 (62%) answered “never” or “rarely.” Four answered “sometimes.” No respondent answered “always.” Since taking accurate measurements is critical to managing many medical conditions, it appears that more work could be done to
educate medical professionals about the options that are available to patients with different needs, as well as how to provide instruction.

When asked if a health care practitioner had ever under-reacted or over-reacted to an unrelated medical concern because of a patient’s blindness, half (10, or 50%) said yes and 50% said no. Examples of misdiagnoses are included in the narrative comments at the end of this report. Since effective treatment is dependent upon an accurate diagnosis, Medical professionals would benefit from continuing education about the ways in which vision loss may or may not impact another condition. On a positive note, 90% (18) of respondents said that they had never been denied the option to engage in a medical procedure or protocol because a medical professional had assumed incorrectly that the patient couldn’t perform the functions needed to participate.

Slightly more than half of respondents (12, or 60%) said they had sought psychological counseling. Of those who were in counseling, 8 respondents (66%) reported that the therapist was excellent or understood the impact of disability on their situation fairly well after an explanation. One-third (4, or 33%) said the degree of understanding was either “not much” or the therapist “totally didn’t get it.” While it’s encouraging that people are availing themselves of available resources and the majority are finding it helpful, the data suggest that there is some inconsistency in the quality of the experience.

Three-quarters of respondents (15, or 75%) had been hospitalized as a blind person. When asked to rate their experience, 8 of the 15 (53%) said it was “good.” Four (27%) said the experience was “poor,” and 2 (13%) said it was “average.” One respondent (7%) said their experience was “excellent.” Factors affecting the quality of hospitalization may include the percentage of staff who identify themselves by name, title, and purpose of visit when entering a blind patient’s room, the willingness of staff to explain procedures as they’re being performed, and the availability of assistance with written forms and discharge instructions.

Communication issues were a significant barrier for most survey participants. When asked how often medical professionals had proactively offered written materials (forms, discharge papers, brochures, etc.) in alternative formats such as braille, large print, or audio over the last five years, 75% of respondents (15) said “never.” Four (20%) responded “rarely.” One person (5%) answered “sometimes.” No participant answered “always.” Based on this admittedly small sample, it appears that 95% of the medical practices used by survey participants offered alternative formats only when asked. Many people with visual disabilities have red-and-white canes, service animals, or a sighted guide. The response or lack of response raises troubling questions about the degree of flexibility and outreach that medical professionals offer to populations with less obvious disabilities.

The availability of staff to help fill out forms seemed to vary by practice, with half (10, or 50%) saying “always.” Six (30%) said “sometimes” and 4 (20%) said “rarely” or “never.”

Thirteen respondents (65%) of the 20 said they had requested materials from a medical professional in an alternative format. “Alternative format” had been defined in the previous question as braille, large print, or audio. Reasons for not requesting accessible materials may include the availability of a family member to read hard-copy forms, the patient’s ability to scan
the document at home, the inability of the patient to read braille or use adaptive technology, a willingness to do without the information, or an expectation that the request would not provide a satisfactory result. Of the 13 respondents who said they had made requests, slightly more than half (7 or 54%) said they were not satisfied with the speed, quality, or accuracy of the response. Unsatisfactory experiences may include documents that arrive too late for the information to be useful, braille documents that do not conform to the standards set by the Braille Authority of North America, or large print documents that are made by enlarging documents on a copy machine.

Relying on family members and volunteers to fill out forms and read lab results is experienced by some blind patients as a violation of privacy. It introduces an unnecessary dependence and can create an odd dynamic in interpersonal relationships. Given that more than half of respondents were making requests and that half of those who did were not satisfied, it is possible that more patients would ask if the expectation of satisfaction were higher.

Patients who requested materials in alternative formats were male and female and seemed to represent all age groups and degrees of vision loss. Blind patients are encouraged to be assertive when making requests, and to hold their providers to a standard that they find satisfactory.

When asked how much communication outside of an appointment with their doctors took place through an online patient portal, 12 (60%) said “none.” Three others (15%) said “some.” Four (20%) said “most,” and one (5%) did not answer. Given that 75% of respondents indicated that they got “none” or “some” of their information through online portals, it would seem that this increasingly important method of communicating with patients is not currently an effective and reliable means for medical offices to communicate with blind patients.

Respondents who answered “some” or “none” were asked to explain the reasons for their answer. Seven (47%) said it wasn’t accessible. Three (20%) said they didn’t know how. Three (20%) said the doctor didn’t have a portal. One (7%) said they preferred not to use it, and one didn’t provide a reason. Since only 3 patients in the survey said that their doctor didn’t have a portal, it seems that the majority of blind patients go to clinics where other patients are communicating with medical personnel online.

“Not accessible” means that the website does not conform to the Web Content Accessibility Guidelines (WCAG) 2.0 AA, set by the World Wide Web Consortium (W3C.) Inaccessibility may be caused by the absence of navigational features, PDFs that cannot be read by screen-reading software such as JAWS, and encrypted communication that interferes with adaptive technology. An accessible website can be made inaccessible by the software of a third party vendor. Many individuals who say they don’t know how to use a website are actually describing a site that is not accessible. The exercise of standardizing a website improves accessibility for patients who are deaf or who have fine-motor limitations, and usually makes a site stronger for all users. Since technology is often the best way to provide private communication to all patients, blind or sighted, and lack of accessibility was the most frequently cited reason that blind patients did not use a portal, medical offices that want to improve the care they provide to patients with disabilities are strongly advised to make their websites WCAG compliant.
When asked how often they received medical bills in print although they could not read it easily, 16 (80%) answered “always.” Two (10%) said “sometimes,” 1 (5%) said “rarely,” and 1 (5%) did not answer. No respondent said “never.” Sending a hardcopy bill to a patient who cannot read print contributes to missed payments, confusion, stress, and diminished customer satisfaction. The need to involve a third party in reading one’s medical bill is potentially a violation of privacy, as information about the procedure or the type of doctor seen is disclosed to the person who is assisting the blind patient. Since hardcopy is usually inaccessible, it is especially important that online portals are fully accessible.

Participants were asked to rate how satisfied they were with their overall health care. Half of respondents (10 or 50%) said they were “fairly satisfied.” Six (30%) said they were “very satisfied.” Only 20% said they were “somewhat satisfied” or “not satisfied.”

Given that so many participants reported negative experiences, it is perhaps paradoxical that 80% responded that they were either “very satisfied” or “fairly satisfied” with their overall care. It is possible that participants had occasional negative experiences but had positive experiences most of the time. Massachusetts has some of the finest medical centers in the country, including several that are internationally known. Participant responses may have reflected a high degree of confidence in the providers they saw. Respondents may have had sufficiently good advocacy skills to meet their health goals and navigate around access barriers that would have posed a more serious obstruction to another blind patient. Blindness is a low-incidence disability, and it is also possible that respondents saw their challenges with medical professionals as isolated incidents, rather than as part of a more widespread pattern.

**Conclusion**

Most respondents in the survey had encountered at least one access barrier to health care. Many access barriers were the result of a one-size-fits-all response to patients who had different abilities and needs than non-disabled patients. Some of the barriers to health care access for people who are blind could be removed or lessened by modifying the way that medical professionals communicate with patients who have vision loss. Doctors and staff would benefit from a better understanding of blindness. Collectively and individually, blind patients may need to advocate more assertively for change. Twenty-five years after the enactment of the Americans with Disabilities Act, there is room for improvement. Members of the BSCB would be interested in learning if the issues raised in this informal study are representative of the experiences of blind individuals in general.

Author’s note: This survey was authorized by the BSCB and prepared on its behalf, but any miscalculations, research errors, or conclusions are those of the author and do not necessarily reflect the official position of the BSCB or its board of directors. The questionnaire was designed by DeAnn Elliott of the BSCB and Amy Ruell, President of the NFB of Massachusetts. The BSCB would like to thank Commissioner Saner and Senator Barrett for the opportunity to provide feedback on an issue that is important to blind residents of the Commonwealth.
Narrative Comments (copied from questionnaires):

Broken leg sustained while hiking – the MD said ‘What was someone like YOU doing hiking?’.

When I became a diabetic, they wanted me to come to the clinic everyday so they could take my blood sugar. It was only when I told them that there were accessible devices do do this that they went out and got me one.

They did not know how to work with a blind person and were afraid and overcompensated for their ignorance of blindness.

Comment: Staff helped me fill out forms when necessary, but usually have me answer questions in the waiting area so I had no privacy when giving my answers.

Comment: My newest doctor will not give me the password (for the portal) to even try to access their site. They say that is against the law. They instead mail it to me in print. By the time I receive it, the password has expired: not to mention I am need to find a way to read the print by sighted assistance (and I live alone) or with assistive technology that does not always work adequately.

Once I went to a neurologist for concerns about my memory. The doctor said that the test that they use are all visual so they could not do any testing on me. I asked for alternative tests and they said that there were none.

And once, I went to my Orthopedic doctor to see about a recommended joint replacement and my doctor said that he did not advise it since I am blind and live alone and I would not be able to manage during the recovery since I would not be able to bear weight on my joint and would need to be in a wheelchair on top of my blindness.

On at least two occasions, folks asked if I needed help undressing and putting on a johny coat for minor procedures. Thankfully they were both over ten years ago.

I believe that I have received relatively good healthcare partially because I am extremely extroverted. I hope I’m wrong here, but I suspect that things are more difficult for shy blind persons and, perhaps for women as well. Personal experience with friends and family members suggest that doctors don’t listen as well to women as they do to men.

I had tennis elbow and a doctor diagnosed it as “cane bursitis,” a repetitive motion injury caused by using my red and white cane, and didn’t offer a shot of cortisone because he believed it would just come back. It was treated a year or two later by another doctor who diagnosed it correctly, and the injury has not happened again in the last ten years.

I had a torn meniscus in my knee and a doctor said it was arthritis (a disease associated with the elderly) and suggested I ice it and take aspirin. He was a specialist in sports medicine and attributed it to age. I was a young mother and it was from an injury that I got while walking my first-grader to the bus stop. I hit my knee on a park bench. I was in pain for about 3 years and saw other doctors. I can’t drive, so I walk everywhere, and not being able to walk properly contributed to a delay in getting a guide dog. I finally found a doctor who diagnosed it as a torn meniscus and said he would operate, and surgery fixed the problem. I’ve been 95% pain free for seven years.
I had a perforated tendon in my shoulder after a ski injury. A doctor diagnosed it as bursitis, (another disease sometimes found in the elderly) but it was from a sports/activity injury. I saw another doctor, got a shot of cortisone and some physical therapy, and it went away. I wonder if I’d been a 25 year old able-bodied man if the doctor would have made the same diagnosis. In my experience, there’s a tendency for doctors to see joint pain as arthritis and bursitis when the patient is blind, even if the patient is young and active. Things that are very correctable can get treated as if they’re permanent and they say you have to live with it.

Medical providers need to be able to identify patients with different communication needs and meet those needs, from the patient’s first contact with the office through billing. I have prepped incorrectly for a medical test because I wasn’t able to read or remember the instructions. I’ve had hospital staff enter and leave my room without identifying themselves by name and purpose when I was an in-patient. I’ve had a young male volunteer read my mammogram results because it came in hard copy to my house and it was in the pile of mail that he was helping me process because I couldn’t read it myself. It was embarrassing and a violation of privacy. I’ve had a doctor advise against eye surgery because “You’d just be disappointed,” meaning I think that it wouldn’t cure my blindness, but when I saw another doctor and had the surgery, it helped me quite a lot and I was happy with the results. My baseline was not the same as a patient with better vision, but I should still have the opportunity to benefit from medical treatment as much as possible.

I’m the parent of a teenager who participated in a medical program. Parents were required to read a parent handbook, but it wasn’t online and was only available in hardcopy. I requested a text or Word file (it was about 70 pages long and didn’t scan well.) I made several written requests and they said they’d do it but it didn’t happen. Finally, I got advice from an attorney and left a message on their answering machine that I’d take legal action if they didn’t get the booklet to me, and I had it within a week. It took 9 months of work to get it in a form I could access, by which time my teenager had finished the program. This happened at a Harvard teaching hospital.

Some professionals would have me go with family members, due to the lack of transportation, of which we, as blind people do need in order to go to some professionals, especially those who are in the mental health profession, where information one may want to talk to about with a therapist or psychiatrist is confidential and should not be at the purview of other family members. Thus, even though some doctors in this profession may only take Medicare, there needs to be an exception made to the MassHealth PT1 form requirements that would allow for a blind person to go to a psychologist or psychiatrist that only takes Medicare, and that exception needs to be that whether or not the psychologist takes Medicare, or MassHealth or does not take MassHealth, that under a prescription for transportation, otherwise known as a PT1, Prescription for Medical Transportation, on the basis of blindness, of which in and of itself is a medical condition, MassHealth should provide medical transportation to such above-mentioned providers, so long as the blind or transportation disabled person, who through no choice of their own cannot get a driver’s license due to a transportation related disability, such as blindness gets a PT1 filled out by their primary care physician.
(I had) A reaction to a vaccine caused me many medical issues which baffled most and some blamed on my blindness. I was refused to be treated by one neurologist because I was blind and she said she could not treat me because of it as she knew nothing about it.

The doctor would not perform a maneuver on me that is used on sighted people because of my blindness saying there would be no way to tell what was going on.

A doctor told me I had ‘bone spicules’ on my retina, and I didn’t know what those were. He showed me a photograph, which I couldn’t see…because of the bone spicules on my retina.

I went to the ER for some stitches in my finger. The doctor said I had to get some x-rays to make sure there wasn’t any glass still in the wound. It was 2:00 in the morning and I’d been waiting for more than five hours. I just wanted to get my stitches and go home, so I said I didn’t think the glass had shattered and it was fine. He said my index finger was an important braille finger and he wanted to make sure there was no nerve damage. I had only recently become blind and didn’t read braille, so I wasn’t thinking about it. I was glad he was able to think for me. We need more doctors who can demonstrate that kind of knowledge and leadership. (He was at MGH.)

Three Greatest Barriers:
1. Having to advocate for accessibility when what I should be focused on is getting good health care.
2. Having to rely on others to assist me in filling out medical papers of a personal nature.
3. Keeping track of the names and purposes of the medications I get from most pharmacies.

Health plan that was more expensive and less inclusive after I stopped working
Transportation issues, ie need to book the day before
Lack of information in accessible format

Nurses not having knowledge to ask me a question and instead asking their colleagues how do I talk to the patient. Having to ask in advance for forms to complete. Teaching professionals how to perform sighted guide.

Financial

1. Transportation
2. Inaccessible test results & hand outs
3. Access - theoretically less so now that I am eligible for The Ride, but new locations unaccompanied are a real challenge.
2. Evaluating health care insurance options (if married and both spouses have this benefit, lots to analyze) and then enrolling
3. Organizing two prescription meds with other over the counter vitamins/aspirin

I do worry if I needed to be hospitalized about being with and care of my guide dog
The occasional doctor with poor bedside manner. That said, I have had minimal contact with healthcare practitioners over the past 5 or 10 years because my health has been generally very good. My visits to the doctor have been minimal.

Transportation to & from appointments or procedures.
Professionals not understanding that I have limited vision.
Have to explain to professions to be very specific in giving directions.
Forms & any instructions aren't in accessible format.
If I do receive information in accessible format it's difficult to obtain it in font size larger than 14 point or in audio format.
Lack of coverage for certain dental procedures such as crowns; Continually having to remind practitioners to provide written information in accessible formats.

1. Access to prescription labeling in alternative format for those who are blind or print reading challenged. At the current time, however, I use a Wal Mart pharmacy up where I live to get my prescriptions refilled due to the fact that they have the Scriptalk system available using RFID to put prescriptions into accessible format so that a blind or deaf/blind person can not only read the prescriptions through the provided loaner patient reader, provided for free to blind persons, through a loner, but, can also produce this type of information on a computer’s monitor through the patient reader’s USB’s interface and also the Scriptalk user Interface software, which comes with the patient reader.

2. Financial barriers, due to the fact that MassHealth does not cover much in the way of dental benefits. I am going to need an oral appliance to treat a newly diagnosed case of mild sleep apnea and at the current time, these dentists who make them either do not accept MassHealth and only Medicare, which covers 80% of the approved amount and the patient has to pay the rest. Note: these oral appliances that treat mild OSA otherwise known as mild Obstructive Sleep Apnea, can cost upwards from $700.00-$2,000.00

3. Inadequate transportation services to doctors who only take Medicare, but, not MassHealth, such as for instance, psychologist and psychiatrists or oral surgeons or specialized dentists who treat sleep apnea.

Also, relating back to an experience I had back on September 28, 2014. I started seeing a rainbow hallow around my left eye at 10:0 PM that night. I called my eye doctor and found out that the office was closed and that only the answering service was available. When the doctor called me back, he suggested that I wait until the next morning to come in. Due to past history with my eyes, resultant from my mother having the German Measles when she was pregnant with me, my first eye doctor who had done my eye surgeries had always told me and my mother that if anything went wrong with my eyes that I was to have them checked out immediately. This resulted in me having to take an ambulance to Holy Family Hospital in Methuen, Massachusetts, who does not even have the equipment or the specialists to use the equipment to check eyes or diagnose eye problems, thus, another ambulance had to be called for me to go from Holy family hospital to Mass Eye and Ear Infirmary in Boston, Massachusetts, where they do have the equipment to check eyes and always has a specialist in the emergency room. There is a more cost effective way to provide emergency medical transportation to medical facilities to check eyes. I had asked to go straight to MEEI, but, because of my location and the ambulance services used in my location, I had to take two different ambulances just to have my eyes checked out, when for less money,. The state could had considered using and bargaining with a
taxi company to go to places such as Mass Eye and Ear Infirmary and then back home. Why? Because, Mss Eye and Ear in Boston are the only people when it comes to emergencies with the eyes are the only people who can adequately diagnose eye problems, because, again, local hospital ER’s do not have either the equipment or specialist who can diagnose or check out eyes in emergency situations, and thus, waiting until the next day, especially for someone with eye problems can end up to be very detrimental to the health of the persons’ eye.

On another note, going back to psychology and psychiatry. Given the crimes that are going on and the mental health issue sometimes faced by the individuals who may engage in unpredictable violent behaviors, these kinds of services should in no way be compromised. Furthermore, if someone who knows that they may have some psychological disorder such as PTSD for example, and thinks that something may be going aerie with either their treatment or their medications, and think that they may need second opinions on the matter, finding a mental health professional or doctor to conduct this objective evaluation should not be like a job search. At this time, someone is not looking for employment or to attend school. Furthermore, this kind of issue is not American Idol with Ryan Seacrest or Keeping Up with the Kardashians. Looking for health services should not be like doing a job search. This is why privatization only works to a certain extent. Thus, this is why the state needs to regulate healthcare services a little better or these people who administer continuing education for board re-certification examinations of healthcare professionals, such as doctors might as well throw these re-certification and continuing education courses away if these healthcare professionals are not going to be kept updated on the latest accessibility technology or laws regarding access to healthcare to the disabled and the same should also hold true for lawyers.

Alternate access to print materials at doctor, dentist and hospital
Convenient Transportation for appointments, blood tests, and physical therapy
Accessible prescription bottles and information from Stop and Shop pharmacy

Inaccurate diagnosis, communication access, inaccessible prescription labels

Transportation/convenience in getting there.
Inability to read printed material provided by providers
Inaccessible bills

3. Medicine is too costly.
2. Doctors like to play god and hide their own mistakes behind the white wall of silence.
1. Quality health care does not exist as we have a for profit health care system that is designed to destroy patients financially by treating illness not curing illness.

1. Health Insurance coverage - particularly for dental care.
2. Transportation for various medical appointments as well as to pick up prescriptions.
3. The understanding by medical professionals regarding how or how not my Blindness may or may not impact my health and when or when not it is a limitation to living a healthy lifestyle or able to receive the best health care possible.

Difficulty getting timely appointments
Difficulty with transportation
Information (discharge, etc.) not provided in accessible format

1. Doctors (specialists) only looking at the part of the body that is their expertise so there is no communication between doctors and they expects the patient to do the communicating.
2. Many doctors wonder how blindness plays a role in some of my complaints.
3. Doctors do not understand the hoops I have to jump through to get to their facilities when a simple telephone call would suffice.

Access to Health Care Questionnaire
Distributed by the Bay State Council of the Blind and the National Federation of the Blind

Dear BSCB and NFBMA Members and friends:

Please find below a brief (10 minute) questionnaire that has been approved by the BSCB board. We would very much appreciate your participation.

State Senator Michael Barrett (D Lexington) is concerned that Massachusetts residents with disabilities are not receiving the same quality of health care as people without disabilities. He has introduced a bill (S. 565) to create an Office of Health Equity that would establish goals, recommend policies, and work with other agencies to reduce the differences in health care that are often experienced by patients due to disability, race, and ethnicity. Commissioner Paul Saner of the Mass. Commission for the Blind has asked the BSCB and the NFB of Massachusetts to survey our members to learn about the experiences of blind patients. After removing names from the responses, the BSCB and the NFBMA will prepare a brief summary, which will be sent to Sen. Barrett through the MCB.

To complete the questionnaire below, simply forward it (Control F) and enter the following address in the “To” field: deann.elliott@gmail.com. You can type your answers directly on the form. If a response is to be chosen from a list, place an x in front of that choice. When you’re finished, press enter. Please do not reply directly to this form.

While this process is more private than putting information on a website, we do not encourage you to give highly personal information, as we cannot guarantee total confidentiality.

Thank you very much for your participation and feedback. Please return all responses by May 17, 2015. A summary of our findings will be available through the BSCB and the NFBMA.

Demographic Data:
Are you:
Male
Female
Transgendered

Age:
Under 25
25-34
35-44
45-54
55-64
65 or over

Visual impairment:
Totally blind
Very limited vision
Some usable vision

Have you ever chosen a doctor because his or her office was easy to get to, when you would have gone to a different doctor if you had had other transportation options?
Yes
No

Has a medical professional ever explained something to you using visual aids (such as a graph, photo, or model) that left you feeling you understood the information less well than if another communication technique had been used?
Yes
No

In the last five years, how often have medical professionals proactively offered written materials to you (forms, discharge papers, brochures, etc.) in alternative formats such as braille, large print, or audio?
Always
Sometimes
Rarely
Never

If you had to fill out forms either prior to or during a medical appointment, how willing and available were staff to accommodate your needs?
Always
Sometimes
Rarely
Never

Have you ever requested materials from a medical professional in an alternative format?
Yes
No

If yes, were you satisfied with the speed, quality, and accuracy of the response?
Yes
No
What portion of your communication with your doctors takes place through an online patient portal?
Most communication outside of appointment
Some communication
None

If the answer is “some” or “none,” please choose the reason that best describes your response:
My doctors don’t have an online portal
I prefer not to use the portal
I don’t know how to use the portal
The portal isn’t accessible using my adaptive technology

How often do you receive medical bills in print although you cannot read it easily?
Always
Sometimes
Rarely
Never
Not applicable

If you have a medical condition that requires you to take measurements, such as hypertension or diabetes, are the professionals who work with you aware of and able to provide guidance around obtaining and using adaptive devices?
Always
Sometimes
Rarely
Never

Have you ever postponed medical treatment, including filling prescriptions and dental care, due to financial concerns?
Yes
No

Have you ever felt that a health care practitioner under-reacted or over-reacted to an unrelated medical concern because of your blindness?
Yes
No
If yes, please explain.

Have you ever been denied the option to engage in a medical procedure or protocol for a medical condition because the medical professionals involved assumed that you could not perform the functions needed to participate?
Yes
No
If yes, briefly explain.

Have you been hospitalized as a blind person?
Yes
No

If yes, how would you rate your experience?
Excellent
Good
Average
Poor

If you have ever been in counseling, how well did the psychologist, social worker, or therapist understand the impact of disability on your situation?
Extremely well
Fairly well, after an explanation
Not much
Totally didn’t get it

How satisfied are you with the overall health care you receive?
Very satisfied
Fairly satisfied
Somewhat satisfied
Not satisfied

What are the 3 greatest barriers you have experienced in obtaining quality medical care?

Thank you for your time. If you have any information you would like to share, please feel free to leave a brief comment.