

Interviewee: Ona Stewart
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Interviewed by Kelly Skeuse on February 19th, 2008

Abstract: Ona Stewart was born and raised in Maine and now lives in Cambridge, MA. In this interview, Ona talks about the challenging experiences and rewarding accomplishments of being deaf and blind. In Maine, she was educated at Governor Baxter School for the Deaf where she learned her native language, American Sign Language (ASL). With the use of ASL as her primary source of communication, Ona has flourished in the Deaf and DeafBlind communities and cultures. In contrast to the complete communication in the Deaf and DeafBlind communities, Ona must work hard to linguistically connect to the hearing world. Ona speaks about her determination to overcome the communication challenges with her family and co-workers. Ona also discusses the services provided by difference DeafBlind advocacy programs in Massachusetts, such as Deaf Blind Community Access Network (DBCAN) and Deaf Blind Community Contact Center (DBCC). Through these services, the DeafBlind community can continue to stay connected and active in the hearing communities in which they live. Although faced with obstacles, Ona thrives as an independent and self-sufficient woman who is determined to stay healthy and stay active.

Kelly Skeuse: Where were you born and what year?

Ona Stewart: Well, I was born in Maine.

KS: Okay, what year?

OS: Do you mean what year I was born?

KS: Yes.

OS: Oh, you're cut, excuse me. I was born in 1958.

KS: Okay, I see. Tell me about your parents. Are they deaf, or deaf/blind?

OS: Oh no, both of my parents are deceased, I have 5 brothers, and 2 sisters, but they are all hearing. I am the only deaf/blind one in the family, and I was born last, I'm the baby.

KS: Oh okay, are your brothers or sisters deaf or blind?

OS: No, I just told you, I have 5 brothers and 2 sisters, and they're all hearing.

KS: Oh okay I see. When you became deaf/blind what was your family's reaction?

OS: Hmm, you mean what my family reacted? Well they were all hearing, like I said, and I was born deaf. I went to school in Maine at the Governor Baxter School for the Deaf and there I was able to learn sign language and become very fluent in it. Then when I was around 19 I started having visual problems. I started seeing black spots and it just got really hard to see. I started using glasses; I guess that was about the time when I started having tunnel vision. My peripheral vision started to go away, not all the way, but it started to limit my vision.

KS: Oh, okay. What age did your vision become tunnel vision?

OS: Well, I just told you that story, but it really happened in stages. One moment I could see and I was fine, if there was a sign if everyone could see everything, but then I didn't understand why I, I just kept bumping into people. Why was that happening? I thought they were rude, and they thought I was rude. Why were we bumping into each other? And they said it was from my tunnel vision. So, I started to figure out that it was my vision that was failing me. It was really bad at nighttime, I just couldn't see at all. When I was around age 28, I think it was the year 1988, well maybe it was 1984, I'm not exactly sure of the year, but I just, my vision just kept getting worse and I went to the doctor and he diagnosed me with cataracts, fuzzy vision, and all that goes with that. Later I was re-diagnosed with retinitis pigmentosa, and the colors just really started to change with my vision. It was really uncomfortable and I became really scared and embarrassed when things would happen like that. I think that was around 1991 or '92. And recently, just a couple years ago, my vision started becoming really hazy, I went to the doctor and he said I wasn't losing my entire vision it was starting to level out, but I have my good and my bad days. So now I start to take vitamin A so my vision doesn't deteriorate all the way.

KS: Wow, I see. That must have been hard. When you were growing up, how did you communicate with your family?

OS: Hmm, well, I remember when I was growing up we did a lot of gesturing. A lot of just visual communication, getting the meaning across. Later there was a family situation that changed everything. My mother, she actually passed away when I was about 5 years old. My father remarried, and my stepmom and I gestured back and forth until I was about 22 and 23 on and it started to become really uncomfortable, so we started to write

back and forth, especially with my brothers and sisters. I wouldn't use pencil or pen but it started to get really hard to ever see that. I told them they had to use dark, black ink, make it thick so I can see it, but they just didn't understand, they kept writing normally. My family just sometimes doesn't understand my problems, especially when the writing became all over the page. I just told them to write, but they don't understand me sometimes.

KS: I see. Did you go to college?

OS: No, no, I never went to college.

KS: Okay. And what year did you move to Cambridge, and also why?

OS: Uh, well, like I said, up until now living here it's just been amazing. I've lived here for 30 years. A while back, when I was going to the Perkins School for the Blind, I decided that there was just too much hearing influence, so I narrowed my choices down to three schools, Wisconsin, Maine, and Massachusetts. I was really motivated to get out and meet deaf people. At that time I was really shy, especially when I started to lose my vision. It was just hard for me to accept it, and so I wanted to get out there and meet a lot of friends and I was really fortunate, and I did.

KS: I see. Where do you work, [pause] and what do you do there?

OS: I'm sorry, what was that? Work and what else?

KS: You do what at work?

OS: Oh, okay. Well, did a lot of jobs over the years. Before I came here, I worked at community workshops. Well it wasn't exactly a workshop, it was a little different but what we had was all these different classes; like vocational training. We learned how to clean, and we did some surveying, even packaging different items. I worked there for one or two years until I decided to transfer jobs. And that was when I went to Massachusetts at Ferdinand. There I did a lot of janitorial work in the dorms, but I quit that job. It was too much of a commute and every night I would be so tired. Then I worked at Harvard Medical. I worked in the hospital area; I did janitorial work there too cleaning up different things but I had a lot of problems there and I quit. Next I worked at Lotus. I worked on an assembly line. I put different things together and I was able to gesture back and forth with the other hearing workers and figure out what goes with what. I worked there for only one year and I was really sad when it closed down and moved to another town. Finally I got the job that I have today. I work at Gateway Crafts I do a lot of different activities there, pottery being one of them. They taught me through an interpreter how to do it and now I'm able to teach other people how to mold the clay up into beautiful pots. It's so much fun. I also do some weaving of looms, fabric design, and just different things working in the craft store and I've worked there for a long time; almost 13 years, I just love it there.

KS: Wow, you have had many, many jobs.

OS: Ha, yup.

KS: At work do you have any challenges with communication? Tell me about that.

OS: Do you mean at work how do I communicate or...?

KS: Do you have challenges?

OS: I'm not understanding...

KS: With communication?

OS: I'm not understanding the sign.

KS: C H A L L E N G E S (spelled out)

OS: Oh, I sign that like this. Okay. Oh well but I'm still not exactly sure what you mean.

KS: Do you have an interpreter with you at work?

OS: Okay, um (pause)...Do you mean the different forms of communication? How do I match them up? I think it really depends on the person. Some people really don't understand my strong ASL signing. They get a little nervous at first, but I just tell them be patient, they'll get accustomed to it later. Also, back when I had good vision I was able to work with a lot of different interpreters and go out in the deaf community, but no I understand it's a little bit different. And some people really are nervous to do tactile signing they just don't want to put their hands on mine. And some of them really don't understand the deaf culture, they're really uncomfortable especially with deaf/blind that we actually need to make contact, with our hands. Some later are able to be accustomed to it and they understand what needs to go on. And they other people get confused that since I have a little bit of vision that they think that I can see, but I tell them 'No, I really am deaf/blind, I'm legally blind, I need to track your hands.' So I guess it just really depends on the person. Like with you I'm using Pigeon Sign Language and we're just able to match our languages so that we're able to communicate.

KS: Oh, okay, I see. Do you live in an apartment, or a condo...?

OS: Oh no, uh well, do you mean condo, do you mean do I rent my own place here? Well I have since '88 (1988). Before I moved here, I live kind of close just in the area over there, for about 13 years before I decided to move here. Sorry I lost my train of thought. Yes I think it was about '87 (1987), I just didn't feel safe there at all. It was so far away and I really like to be independent and to be able to go out at night by myself. I like to be

able to use my cane, use the MBTA, although I'm still not comfortable using The Ride, I refuse to use it; a lot of other deaf people use it, but I guess I'm just chicken.

KS: Okay, I see. Do you live alone, or do you have a roommate?

OS: No, I've always preferred to live alone. I feel more comfortable that way.

KS: Okay. When you travel around the city do you use SSP?

OS: It really kind of depends. I enjoy being independent, and before the computer came out it was very difficult for me to find an SSP and we do have DBCC which stands for Deaf Community, Deaf Blind Community Network, Contact Center...sorry. And I use interpreters, I use SSP's through them. I've gone to the ASL festival that way, Deaf Inc Health Fair, I've done that and some other general deaf community events. The uh other, now with the computer I can use the list of Mass DeafTep and be able to find, occasionally find an SSP that way. Now let me explain, there's a difference between an SSP and a provider. A provider works through DBCAN, D B C A N [spells out] which stands for Deaf Blind Access Community Network, that's where Alave Ducharme works, you remember her? DVCAN that's where providers work through; they have a limit of, I have 16 hours a week that I work with, and I use them for going grocery shopping or going places that I am uncomfortable going to alone so I ask a provider to go with me. Unfortunately if things aren't, their schedule is too busy or they get sick my needs are just not met and it's very difficult for me to get a provider. Some deaf/blind people have it a little easier because they have a little bit more vision than I do and they're a little bit more independent than I am. It's a little sad.

KS: Okay, I see. Tell me about a time that you needed an SSP but you couldn't get one.

OS: Do you mean? Well sometimes [pause] sometimes it's very frustrating for deaf/blind people to get an SSP. One place to find an SSP is through the use of Mass DeafTep, occasionally I... you can send out an e-mail and ask for someone to be your SSP. Sometimes those SSP's haven't had a lot of experience signing, especially hearing SSP's so sometimes it's difficult to find someone who matches. And also a lot of them are college students and they have schedule conflicts, so that's very difficult. If I happen to find someone that I work well with and we become friends then I will constantly ask them to be my SSP, and I know if I look at 'em and they start smiling at me, then I know everything's okay and, and they'll work for me. That's works for several different events, the ASL festival, Deaf Inc Health Fair, and it's for those things it's very easy for me to find an SSP. For general community events, it's kind of hit and miss.

KS: Okay, I see.

OS: Sometimes it's, some SSP's are not very skilled with ASL and I don't mind helping them out I, I can teach someone I've worked a lot with SSP's and so it's very easy for me to work but some deaf/blind people refuse to work with someone who doesn't have a lot

of skill. And SSP's if they're not haven't been working very long they feel that tactile signing is very physically exhausting and if you have to go to something all day it can get very tiring. You always need to have another person with you, at least have two SSP's if it's an all day event. Now SSP's work through the DBCC and they are volunteers, but providers are paid, and you know if I'm going to go to a play or something then I take a provider, otherwise if it's a free event I'll take an SSP.

KS: Okay great. In your free time, what do you like to do?

OS: I'm sorry, I didn't get that...

KS: Free, F R E E (spelled out).

OS: Free?

KS: Yes, your free time?

OS: You mean my free time? I'm not too sure what you're talking about.

KS: Yes. Your [pause] free time...what do you like to do?

OS: My who? It's very difficult sometimes to have free time. I'm not one of those people who likes to sit online, always be alone, I always prefer to go out uh sometimes go out with friends, have fun. During the week it's easy to , to schedule events to go out and have fun, the weekend is much more difficult. It can be done, but it's a lot more difficult to have any free time to go out and do anything on the weekend.

KS: Okay, great. What are your future goals?

OS: Well, let me think about it. Really I have several goals, but they're not easy goals. I, I always worked a lot. I, I like working but sometimes that, that's becoming difficult these days and I've always spent a lot of time monitoring myself and trying to figure out who I am and what things I need to take care of myself, to be healthy. I've always wanted to move out of state but it's very difficult because I require deaf/blind services. I do work a lot, but it's difficult because my vision is starting to deteriorate. There are a lot of people who see me and they're shocked and it's kind of scary. Now I'd really like to keep up my energy, keep working, stay healthy. I, I don't want to sit around and not do anything I want to be active. Now that my vision is going it's kind of difficult to work but I still want to be active and do things.

KS: [Long pause] Okay, I see. What do you want people to remember about your life history?

OS: You mean my history, like my past? What, what I've learned or how to sign or just general information?

KS: Um, What do you want people to remember about you?

OS: Well, that's w- are you f- are you nervous? Well I wonder how people who learn about the deaf, deaf/blind communities? Or how to communicate?

KS: Yes, that's right.

OS: I feel that everyone's pretty much the same. Sometimes it's difficult for educational access but everyone pretty much thinks the same, and if we need help then there's always someone there to help and advise is, is important to hear. And it's always good to express your feelings and not hold stuff in, not bottle it up inside. I always enjoy, I always go to work and I enjoy workshops and who I get to know, how to stay healthy and I, I've always hoped that our community can grow and expand and we can meet other people, especially people from other countries. And continue to sign. Now, in regards to my family it's very difficult, I don't really have a lot of contact with them anymore. I spend a lot of time just focusing on myself and how my body works and understanding myself personally. I, I go to a lot of workshops that help that out.

KS: That's great, thank you. I think we're finished.

OS: Oh, one more thing before we go. Before we were talking about how I went to the Governor Baxter School for the Deaf in Maine, I, it's kind of -- I never graduated from there, I moved to the Wisconsin School for the Deaf. It was a severe culture shock for me the environment was much different than I was used to. In Maine everything was very laid back and relaxed and comfortable, in Wisconsin it was very strict; all the students had chores they had to do like serving lunches or cleaning tables, that type of thing. Anyway in 1987 I graduated there and went to Perkins School for the Blind and I didn't feel like I really belonged there; my vision wasn't that bad, but they taught me how to use a cane, and how to use different types of technology, and how to use brail. Later I went to the Helen Keller Center after I was diagnosed with cataracts. Now that Helen Keller Center is in New York, on Long Island. When I went there I was very apprehensive, they told me a lot of different things; they taught me how to use an interpreter, and had different activities. They also had a psychiatrist and we learned how to express our emotions and not bottle stuff in. Now, when I was in Massachusetts at the Perkins School, every- you know- there was a lot of support there and I really enjoyed it, I also enjoyed being DBCC, but I, I was still very depressed and I held things in and I wasn't expressing my emotions so the school in Helen Keller Center really helped me out, the psychiatrist there helped me out to express myself. I was at the Helen Keller Center for one year, and I was at the Perkins School for two years. Now that my vision has started to, starting to get worse, I'm seriously considering going back to the Helen Keller Center and learning more about different types of technology and do more in-depth. I'm also starting to learn grade 2 Braille, I know it's going to be difficult, but you know, I'm still going to try it.

KS: Well, great, thank you. I think we're finished, thank you.