Interviewee: Elaine Ducharme
Interviewer: Jessica Acox
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ASL Interpreters: Veronica Chitwood
Amanda Herring

Abstract: Elaine Ducahrme was born in 1957 in Connecticut. She was born deaf and became blind later in life. She has two sisters and one brother who is also deaf and blind. She recalls attending the Mystic Oral School for the Deaf where they used lip reading although she prefers sign language for communication. After graduation she attended the Helen Keller National Center on Long Island to learn Braille and other skills. Helen Keller is a role model for her. She talks about how people view deaf and blind people, her difficulties getting a job after graduating from high school, and how technology has improved the lives of deaf and blind people. Eventually she earned a degree in Human Services and moved to Boston where she became Director of the Deaf Blind Contact Center where she helps people with essential living services.

Jessica Acox: What is your name?

Elaine Duchame: Well my name is Elaine and my last name is Ducharme. And my sign name looks like this.

JA: Your sign name, how did you get it?

ED: Well sign names are very important to the deaf identity. It helps us all know who each other are. So instead of having to finger spell everything, we can use a sign name and other deaf people we are talking with understand who we are talking about. Sometimes it can be for appearance, and sometimes it's just the first and last letter of your name; it depends, but we use them as our deaf identity.

JA: When were you born?

ED: I was born and grew up in Connecticut. I was born in 1957. I was actually born deaf first, and became blind later on in life. This is actually because I was born with Usher syndrome, which is something that you may know. It just means that when I was born, I was born deaf and bout the age of 3-4 my vision started to get worst, usually at night I got lowered vision. I could still do things like watch T.V., but then when I became older my eyes began to deteriorate. So when I was about thirteen or fourteen up until I twenty-five, my eye sight steadily declined. It got to the point that I was totally legally blind.

JA: Can you please tell us a little about how you communicate and why?

ED: Well I actually prefer to use sign language, because as I told you before I became blind I was deaf. And I went to a school for the deaf in Connecticut call the Mystic Oral School for the Deaf. And they used an oralist method so it was lip reading and no sign language. I think they actually closed down since I went there, because of budget cuts. But some of the students get so frustrated with having to use reading only, that they would use sign language, just because it was easier to communicate. Which actually came in handy because once I became blind, it was a lot easier to sign using a tactile method, rather than having to use anything oral. It also was nice because when I went to Helen Keller Center, it was easier to sign; it went a lot faster, so I just prefer to use that method.

JA: Growing up, who did you live with?

ED: Well I have a wonderful family. I am actually the oldest in the family. I have two hearing sisters, and then my baby brother and I are both deaf and blind. But I am the oldest, and my brother is the baby. Now my parents always support all four of us. My sister both, well they didn't use to sign…With my family I used to have to lip read, because I had to do the same as I did at school. My parents preferred to voice with me, and I would lip read. But once I became older and my sign went, my parents realized if they were going to communicate with me they would have to learn sign language, just because it would be a lot easier. Subsequently, my sisters are wonderful signers now. One of them works with deaf children in Pennsylvania, in an interpreter access program. And other works with special needs child, at a public school in Connecticut. I actually have great support from my family, and my brother actually lives together. We support each other because we are both deaf and blind. And we've become really great friends. But my family as a whole has been a huge source of support. Even my relatives, aunts, uncles and things have suffered through the communication barrier.

JA: Now who did you feel closest with?

ED: Well… My brother, definitely, his name is Paul. And this is his sign name. Now I was actually eleven years older than him, so I acted as his second mother, and that made us really close. But my two sisters and my parents, we are all pretty close. Paul and I are probably the closest, but everybody is important in my life.

JA: Your parents, what did they do for work?

ED: Well my father he is retired, and has been for a very long time now, I think somewhere around twenty-eight years. He used to be a barber though. He used to run the family business with his dad, my grandfather. They had a barber shop in a small town, that has closed since then. He has been retired for long time. My mother was actually a night supervisor. And she never actually got to retire; she worked to the day she died. She actually was 81 years old.

ED: Your father he was a priest, right?

JA: Actually a long time ago, he was studying to be a priest. Before he got married, he was in seminary school. He loved the church. He was an altar boy growing up, from probably about seven years old to eighteen. Where he then went off to college to become a priest, but he found out he did not like school. So one semester he withdrew to go home and worked with father in the barber shop. He ended up staying there, got married and had us kids. But he always continued to stay active in church, and supported the community for that. He was never really a priest but he liked the church.

JA: So growing up you went to church a lot.

ED: Oh yeah. Every Sunday, since I was a baby. It was hard for me in church because I was the only deaf person, and everyone else was hearing. I could not really pay attention, my father used to get so angry. But I always go. Even when I was older my parents told me once I left home I didn't have to go. But if I ever went home, I would still go to church. My sister would interpret for me. I don't really go to church on my own, its only when I go home to visit my father. I go to support him.

JA: Who is one of your role models?

Actually, I have a funny story about that; I will try to keep it quick. But when I was younger, this is one of my favorite stories; my school was having a book fair. And a group of us was looking through the books, there were stacks of books everywhere, and that's when I noticed one book, it was pretty thick and had a beautiful cover. I looked at the name and it said "The Life of

Helen Keller" it was a really big book, so I brought it home to show my mom. I had no idea who Helen Keller was at that time, neither did my mother. I never read it; I kept it and put it away in a desk, until I was about thirteen. Then I saw the movie The Miracle Broker and just became fascinated by Helen Keller's stories. So that's when I pulled that book out again, and started reading it. It really got me thinking, and I decided that I would rather be deaf than blind if I had a choice between the two. And so when I turned 27, I became completely blind, that's when I was labeled completely deaf and blind. I don't think I was actually ready for that at the time. But my sister had actually become pregnant. It was the first time I was going to become an aunt. The same month I became completely deaf blind, my sister was having her baby, and she had asked me to be the godmother to her baby; which was really touching. She ended up having a boy, and his name is Mathew, and we baptized him. It was 1984 that year, we had gone to the church and my brother was actually going to be the godfather, and we found the priest for that church was legally blind. And when he met me, he gave me the nickname, Helen Keller II, which was really touching. And so Helen Keller has actually become my role model. She is someone that I have really come to love. I would love to follow in her footsteps.

JA: Schools, when you were growing up, where did you go? Neighborhood schools or different schools?

ED: That is actually a really good question. Well, I didn't go to school in my home town, I went to a residential school, and I lived in the dorms. The school was about…It was the Mystic Oral School, and it was about a half-hour from my house. And the commute was really long for me. Because I started at five, having to drive a half hour to school and a half hour back home was just too much. So I was left in school on Monday, and my parents picked me up every Friday. And when my brother was born, he actually didn't mind the commute. And he started there at three. I just loved school, and I preferred to stay there in the dorm. Because my sisters were scarce, they had their own friends. The dorms were just fun for me, I would play and I had friends, and I was involved in sports, and many other activities, dances and all sorts of things. So my brother commuted from the time he was three to about the age of ten. So seven years he commuted. And then he transferred to a different school for the deaf. The Clark School in Massachusetts, western Massachusetts. He started about ten, and he actually graduated from that school. And I graduated from the Mystic Oral program. And as I said before, I liked to stay there because I had a lot of friends at school, not so many in my hometown of Connecticut.

JA: Did you go to programs for deaf and blind?

ED: Well, when I was growing up there weren’t any programs for deaf and blind. So when I graduated from school, I went to couple different colleges, but they didn’t have any deaf and blind programs, they only had blind programs; learning Braille and mobility. I ended up going to the Helen Keller National Center in New York, in Long Island. It was special training, it was nine months, and we learned Braille and other special skills. And it was a really successful experience for me because I learned a lot of important skills.

JA What kind of programs did you start to support the deaf and blind?

ED: What kind of programs? When I was afflicted with being deaf and blind, I went to a conference; and it was the National Conference of the American Association for the Deaf and Blind. And that conference ended up in Seattle. It was an amazing experience and I learned a lot. So when that conference was over, and I went back to Connecticut, I was discussing some about the experiences I had at the conference. And how there were no deaf blind programs set up in Connecticut. So I decided to go around and talk about the deaf and blind culture, SSB support, and those kinds of things. And later I actually set up a blind club, in 1987. It was the Deaf and Blind Association of Connecticut. And it has been a very successful club; it’s been around for twenty years. And while I used to be on the Board of Directors of that association, I since advocated my role as president. The members have really dwindled in Connecticut for that organization, because move and what not. When I lived here in Boston, I was really lucky to find a job. I work as the director of the DBCS, which is the Deaf Blind Contact Center, because of my leadership abilities. I have also worked at a plethora of local and state organizations, both here and in Connecticut, for the deaf and blind. But I really wanted to focus my work in the community, so I left some of them; although I have been on the, been involved in the American Association for the Deaf and Blind, as well.

JA: At what age did you start working? Growing up maybe sixteen, I don’t know?

ED: I do have work experience. When I was sixteen or seventeen, I had my first job, at a factory. My mother helped me get the job. I made bed spreads and curtains. It was actually a very enjoyable experience. Most of my other co-workers were hearing, so I would teach them sign language for fun. I worked there for a while, then I needed to quit because my grandmother had taken ill, and I needed help my mother take care of my grandmother. And I did that for about three years. When I graduated from school and I went off to college, there were no job opportunities for me. And I would apply for jobs, but I kept getting turned down, it was a very frustrating time for me. I didn't use a cane, and people thought it was funny that I was blind and I had low vision and I didn't use a cane, they felt something was off there. And then I went back to the factory again, and this was after my Helen Keller training, so I was 28. And during that time I was doing a lot of moving, going to different schools. But I went back to work at the factory, but like I said before it was very an enjoyable experience for me, because I enjoyed teaching ASL to my hearing co-workers. And then I quit working at the factory. And then I worked at a private company, with deaf blind services. And since that private company has shut down, which is very sad, and they gave me a pink slip. And I was really sad to let go of that job, and I went back to college and I got my degree in Human Services. I went to a community college in northwestern Connecticut, Connecticut Community College. And I got a job there, and I taught there. I worked there for about five years. And we set a program with deaf blind individuals, and we actually wrote a book and did a video tape with that, with seven other staff. And that was a very good experience as well. And I moved here to Boston and my job here at the DBCC, is my fourth job.

JA: Your job's what, what's your title?

ED: The program here is called the Deaf Blind Contact Center, and it is here in DEAF Inc, which stands for Development Evaluation Adjustment Faculty, Deaf Inc. And it was set up about thirty years ago. So the DBCC was set up about five years ago, in 2001. It was a brand new program; it was actually part of DEAF Inc. And we had a five year contract, and once that was finished I started to look for new work in Connecticut, but I actually got an interview here and that's how I got the job. It was a bit of a challenge to move here from Connecticut. But it was a new program and I decided it was worth it. So what the program did was help people within the state, within area, with essential living services that they needed. And we got help from the Massachusetts Commission for the Deaf and Hard of Hearing. What they would do was, potential clients, they would approve; make sure they were actually deaf blind. And then they would refer the names to me, and I would visit the clients, and meet the one-on-one and do a intake, orientation training with them, and I would teach them how to use our services. I would also bring in new employees that would work as providers. Now they weren’t actually SSP themselves, but they would have to go a 45 hour training to learn how to become providers that we needed. They would have to learn about confidentiality and how to treat each individual with respect. Each client that we had actually had to be above 18, to be entered into our program. What we were teaching was not individual living skills, not proper hygiene and things like that, but to become more independent, so for example how to go to the grocery store. Even though there vision was limited, but not employ the help of friends or family too much, but just to be able to do these things on their own. A lot of deaf and blind people are stuck at home, so small things like read their own mail, our program would help to introduce to them. And our providers we would match up people in the area, close to the deaf and blind person actually lived, usually in the Boston area, maybe Revere sometimes north and south, but nothing far away from Boston as Worcester, for example. But it was the deaf blind person’s responsibility to make their own schedule contact their provider, and figure out how many hours a week their provider would be able work with them. A provider each month was able to work 16 hours a month and go 100 mile allowance themselves. For example, say the client set up every Tuesday as the day that their provider would come; it was up to the client to call the provider, and let them know what their schedule will be. So for every Tuesday the provider would come for four hours, and they might go to the grocery store or to the bank. And once they were done with that they would go to CVS to the pharmacy or maybe even go to a restaurant, thing like that. But it was actually the deaf blind client who made the rules and the schedule, decided for themselves when they would do what, and the provider would just come along for support. I would actually teach the client how to do this. I would teach them what the rules where as well because they needed to know. And then they would get certificated, and it was a pretty successful program. It started to grow in the first two years or so, we have about 67 clients at the moment, but that fluctuates because people will move away or pass on. We actually have ten people on the waiting list at the moment, but we are stumped because we actually don’t have enough money. We started with a grant of $300,000; it has actually been increased to $450,000 which is more proof that it is more successful. I am the director and I have two staff members below me. One is a women name Evelyn, who is the assistant director. She works full-time during the week. And then the other woman’s name is Kendra, she works part-time, she is actually a deaf woman. She works maybe 7 hours. I end up maybe 30 hours out of the week. But its my responsibility to help the clients and the providers know what the rule and boundaries are. I actually pass on some of the responsibility to the clients, so it's up to them to figure out, to know what the rules are, we give them handbooks and things like that. But it has actually been quite successful. There are only two other programs besides the one here in Massachusetts. There is one in Seattle, Washington, and one in Minnesota. Now Massachusetts is actually the one that the other two are basing their research on, so to speak. Ours is the most successful. And personally I use my own provider, which is really nice. It gives me a little impendence; I don't have to rely on my partner or brother as much.

JA: Well it sounds like a wonderful program. So in the future what do you want to do?

ED: I actually have my associate's degree. And I already have a bachelor's degree. My associate's is in General Studies and my bachelor's is in Human Services. I am working on my masters at the moment, as well as a new program here in Boston. Its going to be at the New England Home for the Deaf, for senior citizens. Mainly focusing on senior citizens who are losing their sight. I want to help raise their self-esteem, because there are people who become blind later in life, and have some issues with that. I want to work with elderly deaf, blind, hard of hearing and older people. Set up services for them, to help them when they get older. I don't want them to feel cut off from the world, because soon I will be a senior citizen myself. So it would be nice to get that started for people who lost their vision in their 70s or 80s. And don't quite understand technology and some of the other services we have today. I don't like the idea of them feeling isolated, I want to help them and keep them from the pressures of that. I have actually been to the New England Home for the Deaf twice. I thought when I got there these people would be completely isolated. But actually they weren't. They were alone, but they had really great self-esteem, they knew what they needed. It was actually the staff, nurses, and other deaf people who looked down on them. But they knew themselves that wasn't the way the needed to feel. So the point was really to educate other people and not really them.

JA: That also sounds like a good program. Who funds and gives money for DBCC?

ED: Well DEAF, Inc itself is a non-profit organization. And it was set up 30 years ago. And primarily the first thing they focused on was independent living skills, for users who were deaf and hard of hearing. And they did not offer deaf blind services at that time. So if you needed access with communication or social security or finding a job, those were the things that they were helped with. There was another program, and DEAF, Inc gets a lot there money from the Massachusetts Commission of Deaf and Hard of Hearing. There is another program that has been around DEAF, Inc for a long time, and that was Vocational Evaluation. But sadly, because of budget cuts that program has been cut, and no longer exists. There is also adult education for obtaining your GED, improving your ASL or English, mass studies, trying to become a U.S. citizen; because many deaf people come to the United States from other countries. And they would like to obtain their green card to become U.S. citizens. They get a lot of their money from private organizations, private companies, and donations. There is another program at DEAF, Inc called Project HOPE, and I think that stands for Help Of People and Environment, but I am not sure if I am remembering that correctly. And it is a really good program for deaf, hard of hearing and, deaf blind individuals, who are living with AIDS or HIV. And in the 1970s there were many people dying from this horrible disease and how had contracted it from other drug use or sex. And there have been a lot of new medicines out for the illness. And that program is really good for creating awareness. And it has been a really successful program. And they get their funding from the Massachusetts Public Health Works. And at the DBCC, we get our money a majority of our money from the Massachusetts Commission for the Blind, and that really helps us run. It is a really nice environment at DEAF, Inc because there is a deaf staff, and hearing staff, and a hard of hearing staff. And it's a really good team. It's a very varied team and everybody has access. And because of the fact that our staff is so varied, we can better help our clientele because of that. We are a better representation of that community.

JA: So which do you think is better served, the deaf, blind, hard of hearing, which?

ED: Well I have learned a lot about the Massachusetts Commission for the Blind. And I know about their rules, and how to use their system and services. And every month there is a woman that comes from the Mass Commission, and helps me go over the rules and regulations so I can learn more about the Mass Commission, and their rules and their system. And it has been really great for me to be able help me in my duties as the director of the program. And I gained a lot of information from these sessions. Before I didn't know anything when I was in Connecticut, but the woman in charge of DEAF, Inc has helped me a lot. And she has been very encouraging person. And she is a great leader. She herself is from New York. And she brings a lot of things to DEAF, Inc. One of their substablities I was a little resistant to was their budgeting. But as director I didn't feel comfortable doing that. But I learned a lot about the computers and budgeting; it was a real challenge for me, for me to learn how to follow how to manage our money. For instance, we couldn't take money from one fund and appropriate it to another fund.

JA: So the deaf blind at DEAF, Inc's DBCC, how many live here, work here, and work and have jobs?

ED: Well the deaf blind community really varies, and I have met a lot of them, but I could give you their names. Their ages vary from about 25-80. Individually as people, they are so different, it is impossible to compare them. Their level of hearing ability differs and how much sight they have. So to compare them wouldn't do any good. Some are full-time, some are part-time, and some are homemakers, some are married and have kids at home, some are retired; and it differs from person to person. Some go to college some have not, and the commonality is that even though their personalities are different, they support each other. And the program has been a lot of help getting their self confidence and dignity back. So when people meet me, they think that I must be hearing normal, because they don't expect a deaf blind woman could be the director of this organization. And when I tell them that I am deaf blind, they ask me how I can work, and they don't realize that Braille computers help you do that. I tell them that "Yes we are deaf blind but we can work". And it is really sad that deaf blind people view themselves the way the majority views us. There was a deaf woman who was losing her sight, and she hated deaf blind people. She would not interact with the deaf blind community. And she wanted nothing to do with deaf blind people. She preferred to stay home alone than socialize with deaf people. And she hated the DBCC, and I didn't really understand. She would refuse to accept us. She thought we were weird and wanted to label us. And I told her, and tried to encourage her, just try it. Why not try it? And over time we did. She called me and was lonely. We eventually got her into the program, now she loves it. Although at first she was very resistant to be involved in the community, now she loves socializing with the deaf blind people. And she loves the deaf blind community and enjoys to coming to events; bingo, every month the deaf blind community has bingo, and I enjoy seeing her there. And I have been a role model for her and others. I like to think of my job planting seeds in the deaf community, so they can see they can do this; go to school, work, and have friends; that they don't have to be isolated, they can show people who they really are. They can open up to people, and it is an important part of their identity. They have faith in their abilities and in themselves. Now Connecticut is different, I don't think I would ever want to move back there. I love it here in Massachusetts. And I think I would like to stay. Of people who are deaf blind in Connecticut, the number is very small. And I feel that my time is better spent here. There are many services that I can perform here. Individuals are so positive. In Connecticut, deaf blind people tend to be very depressed, and they have no self-esteem, and very resistant to this whole attitude that the deaf blind people have here in Massachusetts have. And it is a slow process to build up your self-esteem and confidence. And while it is a hard job, a labor of love, and I really love what I do.

JA: How do you use a computer or a phone?

ED: Well that's a really good question. Thank god for technology! If I didn't have any technology, computers, I don't know what I would do. Technology is getting better and better every day. There are people who have low vision, and they have a program so you can see the text, and it's a lot bigger. And it helps blind people with computers, so that they can read, or there are programs with Braille. It reads the Braille in the computer. And there are things that print out Braille. And although a lot of the technology is expensive, some of it is $10,000, it really helps us connect. So you can do MS Word, Excel, you can access your email, and you can go to the Internet and look at Web pages. I have been using a computer for about 15 years. And when I started, I was really no good at it. Well I am not a genius at computers, I am getting there. First I had a computer that had Word Purpose on it, it is a document program. And they came out with Windows 98, which was kind of basic; It had MS Word. And now they have Windows XP, and now I feel awkward all over again. It's like learning from the beginning. And they had TTY with Braille. Well we don't really have pagers that have Braille on them yet. There are phones with Braille, TTY with font for people with low vision. So it's easier to read. And technology has really improved over the last 40 years. I mean think about it, Helen Keller had nothing, she had textile and Braille, and that was all. And now there is such a myriad of technology and options out there for deaf blind individuals. They might even have pagers with Braille in it. And I am actually really excited about that, I would like to get one of those. I really need one. And it really does help improve our lives as deaf blind or blind individuals. Wow this has been a long interview.

JA: We are finished soon. One more question.

ED: Thank goodness!

JA: Do you want to share any advice? Do you have any advice?

ED: Advice? You mean generally or for the deaf blind community?

JA: It doesn’t matter, whatever.

ED: Okay well, I have always been that kind of person that likes to talk, and it’s kind of my personality to talk a lot, talking about problems. And I really enjoy giving advice and helping people out like that. And I am not, by any means, a licensed therapist. But people sharing what’s on their minds, I enjoy that. It doesn’t matter if these people are deaf or blind or hearing impaired; or married, divorced or lesbian or gay. I just enjoy giving advice. It’s always been a part of my personality, just part of who I am. I like to learn about people. And they learn about me, it is kind of an exchange. I do spend a lot of my time chatting, and I get kind of involved in it, I never stop talking. My family used to joke and say that I came out the womb, and was a talking machine. And that’s who I am.

JA: We’re finished. Thank you! And this is going to my school.

ED: Are you going to show it to your class?

JA: We are going to give it to the Worcester Women’s History Project.

ED: Well are they going to understand my signing alright?

JA: Yep.

ED: Alright, Thank You! and Goodbye. I loved it.