

CLAWS AND WINGS:

AN ORAL HISTORY EXPLORATION OF DISABILITY IN DELAWARE 1917-2017

Transcription of video recorded July 28, 2017

Interviewer: Kim Burdick, MA, MPA (Referred to hereafter as KB)

Interviewee: Hailey Shiber (Referred to hereafter as HS), Advocate

Topics included: Communication devices

Run time: 8:29

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HS: Hi. My name is Hailey.

KB: Can you tell us a little bit about your childhood?

HS: I live in Smyrna, Delaware, in the country surrounded by my friends and family. I was very close to my Aunt Trina and best friend, Carly. I like growing up in the country with a big back yard for my sisters and I to play in.

KB: What did you do when you were growing up? Where did you start school?

HS: I went to pre-school at John G. Leach from Easter Seals and transferred to Smyrna School District in kindergarten and first grade. After first grade I was on home-bound teaching with Ms. Tracy, a teacher from Smyrna Middle School. Mom also home-schooled me through a 4H cooperative. I went back to school in 5th grade at J.B.M. [editor: John B. Moore] Middle School part-time until 9th grade. For 9th grade I was transferred to HMS School of Philadelphia for children with cerebral palsy. I like my current school and feel like I fit in.

I had a hard time fitting in at Smyrna, but tried to make friends. I could [editor: could not] do the clubs or the athletic activities or band so it was hard to make friends. I joined Girl Scouts and that was a disaster. In 4H I met great friends and always felt like I fit in. I also feel like I am family in my art therapy studio.

My friend Carly and I have adapted bikes and went on long bike rides together. She got her bike first and then Smyrna Lions Club and the school district along with other private donors bought me mine.

I go to HMS School on every Monday, Tuesday, Thursday, and every other Friday. I attend an art therapy class on Wednesdays. I still see Miss Katie, my speech therapist and am searching for activities that I can do next year after I finish school. When I become an alumni I want to work at my school and volunteer.

KB: What were your dreams? What did you want to be when you grow up?

HS: When I grow up I wanted to be a speech therapist and help Miss Katie, my friend and speech therapist of 7 years. When I first started going to Ms. Katie at Central Delaware Speech and Language I could say only nouns with my speech-generating device. Miss Katie taught me language and sentence formation. My family is supportive of me being a speech therapist but I am not sure what I want to do now. I like to read to children, so that may be something I will do. I also like occupational therapy and have an interest in adapting things. I am just not sure.

KB: Did you ever have a date?

HS: I had a crush on two boys named Louie and Rory. Louie actually moved to Smyrna, which is great. It was not until I went to HMS that I asked a boy to prom and had my first date. It was fun, but I went by myself and with my uncle after that. I have never been in love but hope to some day.

KB: And, tell me about your life now. Where do you live? Do you live with anybody else?

HS: I am an adult now and I live with my mom, dad, and Nana. My other two sisters have moved out to an apartment close by. I am very happy living at home and want to stay at home for now.

KB: Is there anything you want to do that's challenging due to your disability?

HS: Some of the activities that I am interested in doing require more energy than I have. Activities like walking, therapeutic horseback riding, riding my bike, and staying fit with exercise. When I was 10 years old I received a life-saving operation and a trach that helped me to breathe and have more energy. I have a good [unclear] and then orthopedic issues hit me. With my neuromuscular disease I have [unclear] unbalance. It is sometimes like a roller coaster but I love life.

KB: Do you feel that you're treated the same as other people your age?

HS: Yes, I do feel like I am treated equally the same as other people my age with the use of my assisted technology. One time my mom went to a conference at Easter Seals about my speech device. She came back with a roll of duct tape and said that when you don't give Hailey her device to have a voice, it is like putting duct tape on her face. She also proceeded to say, "Would you want that done to you?" The duct tape story comes up once in a while and we all laugh about it, but my mom was serious. Since then, all I know support my voice and make sure I have a say in all that goes on in my life.

KB: So, do you feel like you're in charge of your life?

HS: For the most part I do feel like I am in charge of my own life, but need others on a continual basis to help with my day-to-day living. My nurses are a big part of my life and I need their support. Also, my family gives me support and let me make all my decisions first, when able.

KB: Do you feel like your voice is heard?

HS: I do feel like my voice is being heard through the use of my speech device. And when I am tired I use my facial expressions to assure I am heard. I advocate for myself and others. I like to go with my dad to Legislative Hall to speak to our representatives, teaching them about myself. My family and I have also gone to the Highmark Building, Wilmington, Delaware to appeal health and insurance decisions.

KB: Next question, if you had a magic wand and could change anything, what would it be and how would you change it?

HS: If I had a magic wand I would have went to HMS School earlier because I love the arts and that school is a better setting for me. The people there, especially my teacher, Kevin, believes in me and my abilities, not my disabilities.

KB: If you could tell people one thing about yourself and about your experiences in your lifetime, what would it be? What message do you want history to remember about you?

HS: I love life and everything about it. Do not concentrate on your disability, concentrate on your abilities.

KB: Are you familiar with Americans with Disabilities Act, ADA? What has it done to change your life, your community, your access, and what more needs to change to make your life more accessible?

HS: I am familiar with Americans with Disabilities Act and it has helped me enter buildings and classrooms that were closed once and are now open. Restaurants I like to go to have put ramps in in 2 days for me and others. The restaurant called Bridgeway in Smyrna put a ramp in over days and then called me and my family [to] apologize.

One time I went to IKEA in Philadelphia in my power chair and could not get out of the store the way the exit was built. My sister, Hilary, went up to the manager and quoted Americans with Disabilities Act legislation and they let me out of the gate everybody could exit from instead of going to the back of the store. I had never saw my sister so mad before. The manager looked scared and did the right thing by changing the exit gate.