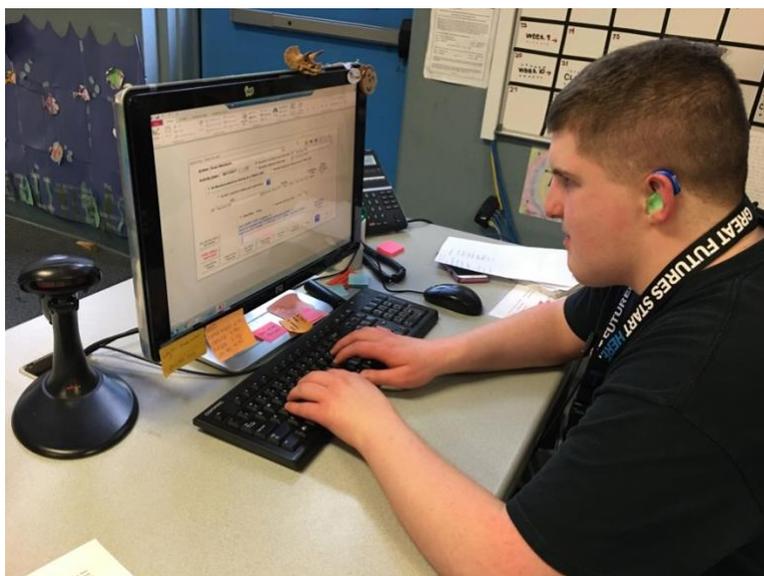


Alex's Story

Below, Alex Steinbrick describes his own transition experiences. He talks about his lessons to live by and the path that led him to an internship with the Boys & Girls Club. April, 2018.

"As a person with a disability, I can say that disabled youth have more in common with their non-disabled classmates than you might think."



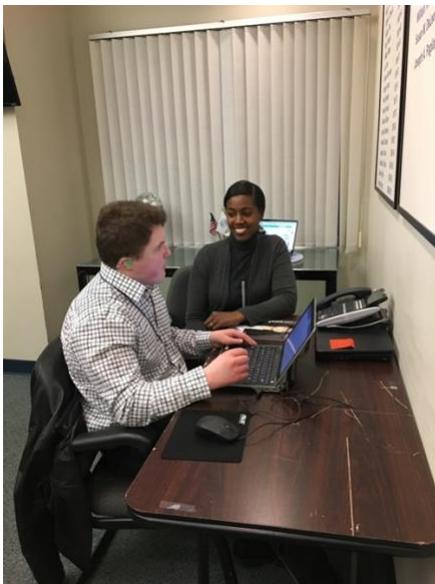
When you hear the word "Transition", most of you reading this article will probably think of it in the same way. It usually means there is a young person with a disability involved, his or her educational team, lots of meetings, and discussions about needs and supports. Every part of the day is planned and there is an adult close by who is responsible for our safety.

Many of my classmates who are not disabled need guidance from their parents, good information to make smart decisions, and most importantly, people around them like good teachers, family, and friends who believe in their abilities and want to help them reach their full potential. As a person with a disability, I can say that disabled youth have more in common with their non-disabled classmates than you might think.

My name is Alex, I am a 19-year-old student who has been attending a public high school in Connecticut for the past five years. I have been diagnosed with CHARGE, which affects my hearing and vision, and some other things. I know that my disability is unique in many ways and it

requires me to be a young person, educator, and advocate all wrapped into one.

I am one of approximately 600 students enrolled here and I am the only student in the school's history who has a combined vision and hearing loss. I consider myself lucky that I have had a good support system, starting with my mom and then expanding to my teachers, guidance counselor, and school administrators. I also have friends and acquaintances, just like any other person in the school. I am part of a small and dedicated community of families and professionals who are familiar with my disability. I am also lucky that I have access to a network of professionals who are experts in CHARGE and deaf-blindness. It was not always like this. Most of the time I was accustomed to schools and communities that had no clue about me or how I live with my disability. The cool thing is that my mom learned a lot from other families and professionals. I think the biggest thing she has taught me was to be self-determined and set goals for myself. In a school in which I am different and chose to go to, I anxiously looked forward to experiencing the challenges that come with my hearing and vision loss.



I share my disability now with a sense of pride because I realize that the challenges it presents provide opportunities for my teachers, principal, job coach, and community to learn. Although I have a lot in common with my classmates, I know that my journey to reach my goals will be different. I am learning as I go and wanted to write this article for parents, my peers, and anyone who can use some of what I have learned along the way.

Lesson 1: You grow as a person by doing, not waiting

It is important to think about transition before the law tells you at what age to start. We are all different and school and state resources are too. We are young adults who are not sure of what we want to do as adults. We all want to be successful and make money, but there are some things that are not in our control. Student development is very important. I knew when I was in the 8th grade that public speaking was interesting. To speak as an advocate for others was my passion. My mother, who is very important in my life, supported my passion. I learned that advocating for others is important but speaking up for my own needs should be first. I supported a coalition of families in Connecticut who fought to stop the state legislature from collapsing programs that would have included vocational rehabilitation services under one umbrella, which would not have been good for families. It was a great experience, because it helped me understand that I would need to make the case for my own needs as an adult and not just while I was a student.

Around the same time, I became an equipment manager for the basketball team, where I learned to advocate for accessibility. I am a huge sports fan and I enjoy basketball very much. I pursued a position on the team as one of the staff to support the players. The school was very willing to support my accessibility needs and I was motivated to be the best equipment manager I could be. I helped the team understand what I needed and brainstormed with the educational team to develop strategies as I faced new challenges. We agreed upon a few strategies—use of hand signals, taps on the shoulders to get my attention during games, note writing on a clipboard, and the use of my FM system. I was the only person on the team who was deaf-blind and it was not easy for me to participate, but I was encouraged by the team's public acknowledgement that I was dedicated and good at my job. The lesson I learned is that part of overcoming obstacles is realizing that if you have high expectations of yourself, others will too.

Lesson 2: It takes a village

We are all aware that special education law says the school is responsible for preparing a deaf-blind student to be independent and ready to work and live in a neighborhood that makes him or her happy. I learned that if I had an idea of what I wanted, what my strengths were, and what made me uncomfortable, it helped the team plan better because they could focus on the most important thing, which was me.

My mother opened a line of communication with my school. She was good at establishing a working relationship with the administration. She was flexible and firm when she needed to be. She soaked up everything she could learn

about my communication and accessibility needs from experts in the region and through parent-to-parent networks.

It makes life easier when you have a supportive principal. My teachers did not know what educating a deaf-blind student entailed, but the principal set a positive tone that I think helped the teachers consider ways to meet my educational and social needs. I participated in my IEP and talked about my classes, what worked and didn't work, and reviewed my accommodations with the team.

Team meetings and IEPs were not always easy because teachers were learning about my needs on the fly and it was different for many of them who typically taught my non-disabled classmates. In some extreme cases, there were some teachers who were reluctant to wear the FM loop system in the classroom and could not understand that no one accommodation would fix everything.

I advocated for accessible materials such as large print, environmental modifications, a note taker, a daily meeting with a resource teacher, emailed assignments, and specific classroom seating. Getting the right accommodations took time, as everyone learned about their roles in making it all come together. The lesson I learned is that flexibility is important, but at the same time, it's essential to be firm about what you think you are entitled to.



Lesson 3: The squeaky wheel gets the oil

It is extremely important for school-age kids to ask for help and guidance from the people we trust most. If a kid is unable to ask for what he needs, or is scared, someone should advocate for him. As a young adult, I am often asked what I want and it is my responsibility to make choices that I think benefit me. I appreciate being asked to make a decisions. At the same time, I want anyone reading this article to know that choosing your family as the main source for decision-making is smart. They know you the best and can

remind you of your limitations, too. This is no different than it is for my non-disabled classmates who play on basketball teams or sit in classrooms studying. The daily decisions we make should always include input from parents and siblings. The more information you have, the better it is for everyone. A student who has family interested in his or her education will be more involved and improve how the school helps prepare him or her for life after school.

My big responsibility as a student was to teach everyone about my disability and educational needs. My mother handed the responsibility of training the school to me. We learned a lot about deaf-blindness through the deaf-blind project, the CHARGE Syndrome Foundation information and training efforts, and from other resources wherever we could get them. The school provided me with time on their professional development day to teach the staff practical things to improve the quality of my educational experience on and off campus.

There are always ongoing challenges, but I learned that I needed someone like my mother who could honestly and positively speak with me about my disability and remind me that some things would be easier for me to do than others. Despite my disability, she expected a lot from me and raised the expectations of everyone on my educational team. She encouraged them to give me an opportunity to make mistakes and learn from them. The lesson I learned is that everyone should be approached the same and not be treated like a fragile painting. You can only learn by doing and making mistakes to and growing from them is all part of maturing.

Lesson 4: Together we can go further

When I was 14, my mom advocated for early work experience for me. My family had decided that our goal was for me to work in a competitive job and that all my educational experiences should build the skills I would need for a career. My mom knew that the most difficult thing would be to encourage school personnel from different backgrounds and with different opinions to work together as a team to prepare me for life after graduation.

I was lucky to have a guidance counselor who thought outside of the box and believed in me. She was committed to working with other members of my school team to create opportunities. The school psychologist worked closely with me on exploring career options. Together, the team developed a plan to explore four career options that matched my interests.

I learned about each career and the responsibilities. This experience was great for me! As I explored these jobs, I learned a lot about myself. There were work tasks I liked and some I did not like! There were some that I could do for a short period of time and some that I would never want to do to make a living. The experience gave me confidence and helped me think

differently about accepting any job as an adult just because someone offers it. I would recommend to anyone reading this article that you should only do jobs you're interested in.

It's important that schools know the community and the kinds of jobs that are available. They should also help vocational rehabilitation see the person before their disability.

Lesson 5: Everyone can work

Everyone can work if given the opportunity. I am still learning about myself and developing a job with the support of vocational rehabilitation has not been easy. I have been offered a lot of work experiences, but have had to advocate for myself to make sure I was not given a job that did not meet my interests and strengths, or take into account the complex challenges caused by my disability. I did not want to fold clothes or use my hands to build things. I appreciated the options, but wanted something different. I wanted things that interested me. I am an advocate and enjoy public speaking. I worked for an attorney at the Center for Disability Rights and the experience reinforced what I already knew. I try to develop my skills whenever I can at places like Mohegan Sun, which hosts events that cater to people within disability communities. My ideal goal is to work in the field of disability.

In Connecticut over the past two years, I have benefited from the Workforce Innovation and Opportunity Act (WIOA). This federal program makes it possible for young adults with disabilities to have opportunities to explore job options, receive counseling, and participate in work-based learning experiences and readiness training to develop social skills and self-advocacy. I am not sure of all the details, but it seemed like WIOA made more resources available for me and provided opportunities to explore other jobs around my interests.

I learned that this federal program funds pre-employment services and that my vocational rehabilitation counselor could develop job opportunities for me with this money. Before receiving WIOA services I worked at the Boys & Girls club in my town and another local program sponsored through my extended school year. The two work experiences were challenging in a couple of ways. I could have used a job coach to assist me with learning work responsibilities and work culture, and to help me adjust my accommodation needs based upon the new environment. I could not stay there long because even though I was self-determined and could advocate for myself, I needed job coach to set things up for me. The other challenge was that specific information that was in my IEP was not followed as much as it was needed to be. I worked through the frustration as best as I could.



The federal WIOA program allowed me to return to my job exploration activities and, with the support of the transition coordinator and a company that develops jobs for disabled people, I got an 80-hour internship at another Boys & Girls club in a different town. I knew that it met my interests and strengths, and with some coaching in what the job was and someone to teach me about the work culture, I would be successful. I learned work etiquette and good social behaviors and I really felt good when I worked there because my job coach gave me room to interact and make my own decisions. I enjoyed assisting the youth leadership group with fundraising and building community awareness, and modeling for them what good citizens are supposed to do. I am currently working part time at the Boys & Girls Club while in school and considering my career and education options after graduation at the end of this school year.