

Testimony by Amelia Wallrich before the
U.S. Senate Committee on Health, Employment, Labor, and Pensions
Lessons From the Field: Learning What Works For Employment For People with
Disabilities
July 14th, 2011

Firstly, I would like to thank Chairman Harkin, Ranking Member Enzi, and the other Committee members for the opportunity to speak today. As a young person with a disability, just beginning my career, it is an incredible honor to be able to share with you a little about my employment and educational experiences and my hopes for the future.

My name is Amelia Wallrich, I am twenty-two years old, and am from Frankfort, Illinois, a small suburb of Chicago. I was born with a rare genetic bone disorder, called Torg Syndrome. I am one of a handful of people in the world with this disorder, and doctors are still researching its root causes, treatments, and the way the disorder progresses. The disease works by causing inflammation in the joints, when a joint becomes inflamed I experience extreme pain and a loss of full movement in those joints. The inflammation has resulted in weakened bones and limited movement in almost every joint. My hands and feet are basically frozen in their positions, and my knees, elbows, and shoulders are limited in their movements. I was 13 months old at the disease's onset, and it has steadily progressed, affecting more joints, as I aged. Because the disorder is so rare, treatment is more of an art than a science, and doctors are unsure how the disorder will progress and affect me in the future. Doctors have tried to slow its progression with intensive physical therapy, various drug therapies, and most recently surgery.

In my day-to-day life, my disability affects how I move. I am able to walk and stand for short periods of time, but mostly I use a motorized scooter. I have difficulty with tasks requiring fine motor skills, for example I write and type more slowly than the average person. Therefore, in the academic setting I use extended time on tests and note taking services. At home, I use devices for putting on my shoes, opening jars, even turning on lights. Additionally, I struggle with unexpected "flare ups," where any type of movement becomes too painful, and I require assistance with basic tasks.

My goal through this testimony is to share my experiences in preparing for the workforce. In doing so, I hope to highlight some of the obstacles facing young people with disabilities seeking employment and some ways these obstacles can be eliminated or minimized. As you will see, I benefitted greatly from mentorships, self-advocacy and leadership training, structured internships, and an inclusive educational environment that understood as young person with a disability I require a customized approach to integrate into the workforce.

Expectations

As young people, we often rise to the expectations society sets for us, whether positive or negative. At a basic level, society needs to learn to have higher expectations for youth with disabilities. Youth with all types of disabilities should be expected to be successful in school, to be permanently employed, and to be active, contributing members of their communities. Higher expectations are a basic foundation for any other supports for people with disabilities. To meet these expectations, youth with disabilities need the same access to opportunities to grow and develop as any young person, but customized to their specific abilities. The path to permanent employment for people with disabilities should include:

- customized support in job seeking and career preparation services
- self-advocacy training that teaches youth how to manage and accommodate their specific disability in the workplace
- leadership training to compliment self-advocacy skills

- opportunities to gain work-related experience through internships and community service activities that allow youth with disabilities to explore their talents and gain new skills in a supportive environment
- access to an inclusive education that teaches youth with disabilities skills that are marketable in the workforce

Every person with a disability will have different strengths, different needs, and access to different resources, but the important thing is that every person with a disability is capable of being a contributing and valued member of the community. Society and employers should be flexible in bringing out the many talents of youth with disabilities and in making accommodations.

A little bit more about my background, I graduated from Lincoln-Way East High School in Frankfort, Illinois in 2007 in the top 3% of my class. I attended the University of Illinois at Urbana-Champaign, where I majored in English and Political Science, graduating in December 2010 cum laude. In August, I will begin law school at Northwestern University. Eventually, I plan to become a lawyer working in disability rights advocacy. I have an older sister who lives and works in Switzerland as a stock trader and analyst. My mother works as a Community Development Director in local government and my stepfather is an instructional designer for food safety training. I benefitted greatly from my parents hard work, both are highly educated and work to offer their children every possible advantage in life. From the time I began preschool, my mother constantly battled to ensure I had the same opportunities as everyone else and never let anyone use my disability as an excuse to hold me back.

I wish I could say the experiences I will share with you are typical for youth with disabilities, but too often they are the exception. In part, much of my relative success has been due to the expectations set by my parents that pushed me to seek out opportunities that would make me competitive in the workforce. It was never a question that I would graduate college, attend law school, get a job, and eventually provide for my own family. My parents' expectations were the same for my sister and I; my disability did not diminish these expectations, it just changed the way I went about achieving my goals. My family's expectations helped me form the expectations I have for myself. These expectations are the basis for all my goals and give me confidence in pursuing new opportunities.

I experienced both high and low expectations from teachers during my educational career. Those with high expectations offered the most support in accommodating my disability and ensuring I was a full participant in the classroom. They were flexible and open to helping me make the most of my abilities. Teachers with low expectations were predictably less supportive. I had to work twice as hard in those classrooms to have the same basic access to learning, and often needed to continually educate these teachers about my disability and remind them of my accommodation needs. Often this resulted in my spending more time trying to accommodate my disability than learning. During college, I found much more consistent support because high expectations and equal access for students with disabilities is a large part of the campus culture and history at the University of Illinois at Urbana-Champaign. The disability services department works on behalf of the student to set up all accommodations, and students with disabilities are active in all aspects of campus life- from Student Senate, to Greek life, to adapted athletics. This type of culture meant I was able to focus fully on working towards my goals and had access to a variety of specialized resources to help me throughout my education and in seeking work experience for future employment.

In the workplace, when employers had high expectations of me, I was given more responsibilities and thus more opportunities to learn new skills. When employers expected very little of me, it was a struggle to receive meaningful projects. With my first internship at Odelson & Sterk, a law firm in Evergreen Park, Illinois, my boss, Burt Odelson, expected me to attend law school and someday be a practicing attorney, so he gave me a variety of projects to introduce me to the work of a lawyer and to help develop my research and writing skills.

Access to Opportunities

In addition to high expectations, I received support in reaching my goals through opportunities to job shadow, perform internships, and hold part-time jobs. I was lucky that my mother worked outside the home in local government and was therefore able to provide me with a range of job shadowing opportunities and introductions. Beginning in junior high, I participated in job shadowing programs in the local government, where a group of students were able to observe the work of local leaders, ask them questions about their careers, and learn about the education and experience needed to attain these positions. Both of my parents also participated in “Take Your Daughter to Work Days” throughout junior high and high school where I had the chance to observe a typical day in a professional setting. This allowed me to observe and understand more about workplace cultures, how meetings are conducted, how employees interact with each other and their bosses, and more basically what is expected of an employee on a day-to-day basis.

These job-shadowing opportunities provided me with connections and confidence to find part-time jobs during high school to further develop my resume. My first job was as a receptionist in a local bank. Finding employment through family and community connections made it much easier for me to transition into the workforce because I did not have to figure out how to “break the ice” about my disability, my boss already knew me and any accommodations I might need. This allowed me to worry less about managing my disability in the workplace and instead focus on learning professional skills. Through my job as a receptionist at the bank and later as a receptionist at a real estate agency, I learned how to interact professionally with customers on the phone and in person, communicate with my supervisors and coworkers in a professional setting, and a variety of other soft skills like using fax machines and copier machines, clerical work such as filing and typing, dressing professionally, and managing a work schedule. Having part-time jobs during high school was also important for building a competitive resume for college admissions. Additionally, it provided me with references and helped me develop a professional reputation for seeking internships in the future.

Having a job also taught me important independent living skills related finances. When I started earning a paycheck, I opened a savings and checking account, and my parents taught me how to balance my checkbook, create a budget, and plan for future expenses. These basic skills started teaching me about responsibility and gave me a preview of adult life.

The next step in my preparation for permanent employment was seeking an internship. Too many students with disabilities do not seek out internships because they do not have access to supports to show them how to disclose their disability in a work environment or how to seek accommodations. Additionally, if there are low expectations of a student with disability in an educational setting, it is unlikely a mentor will push a student with a disability to seek an internship, job shadowing opportunity, or part-time job to further develop their work-related experience. I received guidance from my parents, my University’s disability services

department, and a structured internship program for people with disabilities on the importance of an internship and how to manage my disability in the workplace.

As mentioned, at my first internship at Odelson & Sterk I was fortunate to have a boss who cared a lot about my success and was flexible as I learned how I would need to accommodate my disability in a professional setting. He continually checked in to see how I was navigating the office and introduced me to a wide range of jobs and experiences. He gave me meaningful work so I could gain a holistic view of a lawyer's job. He pushed me to speak with the various attorneys' in the office so I could hear many different perspectives and get advice from a variety of sources. Successfully completing an internship in my field of interest raised the expectations I had for myself and renewed my confidence in seeking permanent employment as a lawyer. More importantly, the internship taught me the practical skills needed to reach my career goals and showed me the steps I would need to take in working towards these goals. This internship experience was essential for developing a professional network that helped me build a stronger resume and provided professional references that helped me seek even more competitive internships and eventually apply to law school.

After my junior year of college, I participated in a structured internship program geared towards mentoring students with disabilities through the American Association of People with Disabilities (AAPD). This internship program provided training on self-advocacy in a professional setting. Through the program I was a Congressional Intern in Senator Durbin's office. This internship was the first job I held without the assistance of family or community connections, which meant I was responsible for communicating information about my disability and any accommodations I would need. AAPD's assistance was key in helping me navigate this new arena, they asked questions about my disability and necessary accommodations that helped me frame how I was going to communicate any issues with the Senator's office. Furthermore, they know a lot about the work environment on Capitol Hill and were able to give me advice about where I should go for assistance for disability-related concerns. AAPD also served as a resource for the Senator's office on how to create an inclusive environment for an intern with a disability.

Through job shadowing, part time jobs, and internship experiences I gained more confidence in defining my career goals, but more importantly I learned skills to help me work towards these goals. I learned what is expected of an employee and how I can meet those expectations. I have steadily taken on more and more of the responsibilities of living independently as an adult as a result of these work experiences; and I have immense satisfaction in being a valued and contributing member of society.

Supports

I was able to gain access to various educational and employment opportunities, and perform successfully in these settings, because of the support of mentors and accommodations. Through family connections I had access to various types of lawyers and a local judge whom I could seek advice from and ask career-related questions. These mentors provided guidance on what I should study during college, the importance of internships, and even on beneficial extracurricular activities. Through my internship with AAPD I gained access to mentors with disabilities, mentors active in the disability community, and peer-to-peer mentors. These mentors were able to offer me valuable perspectives on living successfully and independently with a disability. They further offered examples and strategies of how to request accommodations and even on specific accommodations that could make me more successful in

the workplace. I continue to use these mentors as a resource in goal setting and working towards career goals.

I need fewer accommodations in the work setting than in the classroom, in part because I have benefitted from the support of flexible employers and mentors who worked with me to design projects that would allow me to use my talents and abilities. Some of the basic accommodations I have used are flexible work times/ the ability to work from home, limiting work tasks that required heavy lifting, and a place to park my scooter when not in use. In the future, I may make use of more assistive technology, such as speak-to-write programs that would alleviate the need for long hours of typing.

Self-Advocacy and Leadership Training

Finally, self-advocacy and leadership training will further prepare youth with disabilities for permanent employment by teaching them how to communicate effectively about their disabilities and accommodation needs, while giving them confidence to find ways of using their talents and contributing to their community. Self-advocacy takes a lot of practice and the continued support of people who understand a person's specific disability and accommodation needs. During grade school and junior high my mother met with teachers and school officials on a regular basis to educate them about my disability and the accommodations I would need to have equal access to the classroom. She included me in these conversations and continually pushed me to advocate for myself, showing me how to communicate about my disability with teachers and which school officials to go to if I encountered problems. I also benefitted from having the same disability resource aide/teacher from 3rd grade through my graduation from high school, which helped with transitions between schools. Like my mother, she made self-advocacy a top priority, so by the time I reached high school I was able to communicate with my teachers and request disability accommodations on my own, only using her or school counselors when I met resistance. In college and in the workplace, therefore, I was more comfortable communicating independently about my disability and my accommodation needs because I had experience doing so in high school, and I knew where to look if I had questions about ways I could be a better self-advocate.

Moreover, the leadership training I received from community service and extracurricular activities reinforced my advocacy skills. I tried a variety of activities during high school, but focused most of my energy towards Student Council, Speech Team, and Key Club (a community service organization). I learned to work with my fellow students to make improvements to the school and compete in tournaments; my involvement in Student Council led to leadership positions on the Executive Board and eventually President. In college, I was largely involved in Student Senate and an international student organization called AIESEC, where I was a member of the Executive Board and the head of two committees. My experiences in high school and college taught me how to work in a collaborative environment, how to conduct efficient meetings, and even how to speak in front of large groups. These skills taught me leadership qualities to be a better self-advocate, and also provided me with marketable skills when I sought internships and other employment opportunities. I was able to be a fully participating member of all of these activities because there was a basic respect for my disability, and a willingness to make necessary adjustments to allow me to participate.

Conclusion

As you can see I benefitted greatly from a variety of resources as I worked towards my career goals. The biggest resource was my parents' expectation of my success, which pushed me to work hard and seek out opportunities where I could use my talents. Their expectations and support helped me make use of employment, educational, and leadership opportunities. While my experiences are limited to my specific physical disability, the lessons apply to the entire disability community. People with all types of disabilities- intellectual, learning, sensory, physical, and mental health- can be permanently employed if there is a customized approach to their development and a basic willingness to support the growth of their talents and abilities. These approaches need to include access to an inclusive educational environment, self-advocacy and leadership training, mentorships, and opportunities to gain work-related experiences and skills.

As you address major employment and education legislation, I hope you will keep the specific needs of youth with disabilities at the forefront. My experience shows that youth with disabilities are more than willing to work hard if given the proper resources and support to succeed. There are resources out there for the disability community, but they need to expand so they work across systems and disability groups to reach more individuals. As it is, permanent employment for a person with any type of disability is still too often the exception rather than the norm because many in the disability community do not have access to the same resources I did. Access to a lot of these resources comes down to funding. Programs that contribute to the growth and development of youth with disabilities need adequate funding to ensure youth with disabilities have a good start to their lives and can become contributing members of society. The disability community has so much to offer as members of the workforce and members of society, but we need help breaking down barriers to our full participation.

I would like to thank the committee again for the opportunity to share my experiences and speak on such an important topic; it has been a great honor.