Q&A with Jamie Wolfe, Self-advocate and Disabilities Specialist at CDS

Many of the articles in the Summer 2012 issue of delAware, which focuses on the issue of self-advocacy, were based on interviews with several Delawareans, including most of the people who attended the March 2012 self-advocacy summit in Baltimore. They were asked about their personal and/or professional experiences with self-advocacy.

Jamie Wolfe, disabilities specialist at CDS and self-advocate, responded in writing to the interview questions, and some of her responses were included in delAware. Because the full interview contains information that may be valuable to those who are interested in learning more about self-advocacy, we have posted it on this website.

General questions about self-advocacy

**What does self-advocacy mean to you?**
Self-advocacy is the ability to utilize one’s personal power to not only reach long-term goals, but to support every day wants and needs. In other words, self-advocacy is being able to speak up for yourself in order to live the way you choose on a daily and a long-term basis.

**Why is it important?**
It is important, especially for people with disabilities, because when so many professionals are involved in a person’s life, the person needs to be able to communicate what is important to him or her and what his or her short and long-term wants and needs are. If this does not happen, the individual with a disability will be living to serve the expectations of the professionals.

**What is your personal or professional involvement in self-advocacy?**

**Personal involvement:**
Without being able to effectively advocate for myself, my life would be quite different. For example, I had to advocate for supports that I needed to receive my Bachelor of Arts degree. I wanted to attend the Newark campus of the University of Delaware, but my home was in Dover; it would have been impossible for me to commute on a daily basis. The Division of Vocational Rehabilitation was going to cover the costs of tuition, student fees, room and board, books and supplies. The one thing that was not covered was an attendant to assist with my daily needs. Without an attendant, I would be unable to complete everything from activities of daily living to getting in and out of the wheelchair to eating. Transportation from Dover to Newark and back was not a realistic option. Therefore, I appealed the decision and was able to receive attendant support on campus. Other examples of my personal involvement with self-advocacy have revolved around receiving community-based supports so I can avoid institutionalization, and utilizing the transit system to accommodate my needs.

**Professional involvement:**
For many years, I have used my personal experiences and training to develop advocacy methods for systemic change in my role as a professional. This has involved such endeavors as creating numerous legislative bills that focus on individuals with disabilities living in the community. These range from the community attendant services act to an act
requiring commercial facilities to have some type of door-opening device so individuals with mobility impairments can enter the establishment independently. I have held several positions based on advocacy, including my current position as disabilities specialist at the Center for Disabilities Studies.

How did you become a self-advocate?
I became a self-advocate when I started college in order to receive the supports I needed to succeed.

What have you accomplished for yourself or others through your self-advocacy efforts?
I have accomplished many things for myself and others through the efforts. For instance, I am one of the few individuals that has been able to receive 12 hours of home health support by combining funds from the Division of Services for Aging and Adults with Physical Disabilities and the Division of Medicaid and Medical Assistance. Without these supports, I would have been institutionalized. I also have educated legislators about the importance of passing several pieces of legislation that have assisted other individuals with disabilities. These include the “lemon law” for individuals who need assistive technology, funding for Medicaid for workers with disabilities, and Money Follows the Person.

What needs to be done to involve more people with disabilities in advocating for themselves?
Many issues need to be discussed before more individuals with disabilities can truly advocate for themselves. Foremost, the service system that currently exists in Delaware needs to shift its focus from provider-based services to community-based services. In order to receive services from a provider in the state, individuals with disabilities and their families are given a list of services that are provided and are expected to choose from the list. If the individual does not need any of the services or needs something different from what is on the list, it is difficult, if not impossible, to receive service. Services need to be controlled by those who are using them. Until that happens for all individual with disabilities, self-advocacy is very difficult. Self-advocates can help with this process through several methods. First, individuals need to be taught that they have legal and regulatory rights, and they need to know what these rights are. Second, they need to be taught how to advocate for themselves. In other words, individuals with disabilities need to be able to say “I have the right to …” Finally, the need to understand what resources are available is critical. These resources may not be in the disability field, but can be very useful in order to receive support.

Questions about attending the March 2012 self-advocacy summit

Why were you selected to represent Delaware at the summit?
I was selected because I am a graduate of the Partners in Policymaking program. Graduating from the first class, I have had time and experience to enhance my advocacy skills for myself and others.

What was the highlight of your participating in the summit?
I was very excited about the commitment from the Administration on Developmental Disabilities to those who are self-advocates. The staff and commissioner utilized the information given by self-advocates to develop plans and goals for the agency.
Tell about something you learned about that self-advocacy that you weren't aware of.
I was unaware that many states had a cross-disability focus for their People First organization. In other words, many of the organizations did not just focus on intellectual disabilities, but on physical and psychiatric disabilities as well.

What contributions did you make to the plan for Delaware?
I hope I contributed my experience with legislators and policymakers when creating advocacy goals for Delaware. I have a good working relationship with many of the policymakers in the state, and I tried to shed light on strategies that can be used to facilitate policy change based on my relationships.

What do you hope the plan will do for self-advocacy in Delaware?
I hope the plan will allow self-advocates to be the drivers of the state service system. Policies need to surround what individuals want, not what providers or policy makers think people with disabilities want.