

Using self-advocacy to meet life's challenges

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1. How it all began

Self-advocacy has always been a part of my life as long as I can remember. When I was too young to speak up for myself, I had two parents who would speak up for me. The first act of advocacy on the part of my parents was with medical experts and pediatricians. As a toddler, my parents noticed I was experiencing developmental delays and took me to a variety of doctors to determine the cause. One well meaning doctor told my parents frankly "If you want to save yourself a lot of heartache you need to place Edmond in an institution where he can be cared for, because he will become nothing more than a vegetable when he reaches adulthood". Their response was quick and immediate; we will raise our son at our home. This decision and their continued advocacy enabled me to live a full and rich life; a life that was denied to many others in similar circumstances.

2. School days

During the 50's and 60's, if you were a person with a severe disability, obtaining an education was quite a challenge. My first eight years of learning took place in a segregated classroom. It was comprised of students with many different disabilities including behavioral challenges. As you might imagine, even trying to learn the basic 3 R's proved difficult in that environment. Adding to those challenges, I was told when I reached my pre-teen years that I was then expected to help teach the younger students. This actually turned out to be a positive experience because it let me know that I could assist others with disabilities. This foundation

set the stage for a long and rewarding career which has included teaching, training, counseling and advocacy.

My self-advocacy career began when I was a rising high school freshman. That fall, when I returned to school with two classmates, we entered a classroom with 3 stacks of textbooks setting on a table. However, there was one thing missing – the teacher. When we asked our principal about the teacher's whereabouts, we were told that the special education budget did not have funds for a teacher. Then she smiled and said, "Besides, you guys are smart enough to teach yourselves." After a few moments of telling ourselves, "Hey, this is going to be a cool school year," we began to realize we were being denied our right to a high school education. Since I was a bit of an instigator, I suggested we write a letter to the Chesapeake School Superintendent, asking him to intervene on our behalf. I felt somewhat confident the letter might have a positive result because the Superintendent also happened to be a member of the Sunday school class that Dad and I attended. The following Sunday, the Superintendent stopped me after class. He expressed his surprise over our dilemma, and assured me steps would be taken to correct the situation. A couple of weeks later, we had a teacher. This was my first taste of using successful, self-advocacy techniques. It gave me a feeling of empowerment that would follow me all my life.

Although we had a teacher over the next four years, there were situations that arose at school that caused me to continue to practice my self-advocacy skills. When our senior year rolled around, we talked to our teacher about having our own senior prom. Her response was very cold and firm and she said, "Absolutely not, that would take a lot of planning, just for 3 people; I don't have time for that." Again, my classmates and I took

matters into our own hands and enlisted the help of family and friends to plan our own senior prom; including getting the services of a band. The evening was a huge success.

In a final self-advocacy act during high school, my classmates and I worked with our parents and some of our former teachers, to resolve yet another issue. It involved getting a general diploma instead of a special education certificate. A general diploma would allow us the opportunity to pursue a post secondary education, instead of having to settle for a probable sheltered employment placement. By working together, we convinced Chesapeake School administrators to grant us a general diploma. We were also invited to graduate with the rest of the senior class of another local high school, without being segregated. The three of us were tremendously proud of our accomplishments. It was a long struggle, but we finally felt that we were a part of the "high school experience."

3. Using self-advocacy in my early adult life

Unfortunately, the need to use my self-advocacy skills would not end with high school. Remember, this was the 1960's, so, recommendations (just like the ones I received) to find work in a sheltered workshop or selling pencils on a street corner were not unusual. Though not unusual, these suggestions made to me by vocational counselors were unacceptable and I transferred my burgeoning self-advocacy skills to my professional life. I began to network (although that was long before the term became popular) with the director at my former high school. As luck would have it, she was starting a new library program and asked if I would help to organize this new offering. I enthusiastically accepted and enrolled in library science classes at Old Dominion. Though there were a few bumps along the way, I had successfully obtained my first job and become a college student – two dreams that many told me I could never achieve. From that experience, I had gained self confidence and a belief in my abilities that would serve me well throughout my career.

4. Advocating for employment

Even today, finding the right job can still be a very frustrating and daunting task for a person with a disability. The job search process involves not only dealing with vocational counselors, potential employers, super-

visors, and human resource managers but it also means requesting, advocating for, and acquiring reasonable accommodations. Each step of the way is a challenge and it is important to have strong self esteem and an unwavering belief in your abilities. These two qualities are critical when working with a VR counselor and in marketing yourself to potential employers. Your counselor is part of your team – he or she wants you to succeed. In order for that to happen, however, you need to present yourself as a competent and confident potential employee. Once that is accomplished, it is your job to show the employer why you are the best person for the job, and how you will be an asset to the organization. After you have secured employment, you must continue to let your self confidence show to your supervisors. When requesting job accommodations the employee with a disability must respectfully but assertively state how the accommodations will improve their productivity. To do this effectively, I was required to become a subject matter expert in both assistive technology and workplace personal assistance. The latter is a topic that I have written and lectured about extensively. Though not a new concept, I consider it vastly under utilized as a reasonable support for persons with disabilities. My advocacy on this important accommodation continues today.

Using these self-advocacy techniques has always been one of the keys to the success I have enjoyed during my career. It has enabled me to pursue interesting jobs and assignments. As I jokingly tell friends, I had a hard time deciding what I wanted to be when I grew up. As mentioned, I first found employment as a librarian aide and then as a teacher's aide. Next, I moved on to become a peer counselor at one of our Independent Living Centers. Following that, I enjoyed my work as a State Board Administrator but was laid off due to a state budget crunch. Next, I was hired as a Camp Program Director for people with disabilities. I have even tried my hand at being an entrepreneur, co-founding a systems advocacy consultation business with another person with a significant disability. I am currently working as a training associate with the Rehabilitation, Research and Training Center at Virginia Commonwealth University. This summer, the Governor of Virginia appointed me as his Senior Advisor on disability issues. As you can see I have always been a person who enjoyed new challenges and love to try new things. This has especially been true in my employment pursuits.

5. From self to systems advocacy

As I saw how my use of self-advocacy helped me accomplish many things for myself, I knew I wanted to use those skills to help others. In my different careers, I have had many opportunities to show others the value of using self-advocacy skills to make positive changes in their life. This was especially true during my eight years at the Norfolk Independence Center, serving as a peer counselor. I discovered it was not only important to use my voice in the counseling room, but also necessary to move into the community with my message.

However, since I have significant speech impairment, I never expected to be called upon in this role. However, one day as I was preparing to go home around closing time, my intercom buzzed, and it was the Executive Director calling me to her office. My "assignment" was to deliver the Center's budget proposal to our local city council. I quickly found this was not a joke when she reminded me that 60% of my salary came from that city. As I waited to speak, I noticed members of Council were not paying too much attention to people who were speaking ahead of me. When my turn finally came, around 10pm, a very strange thing happened. Although the Center's receptionist was providing voice interpretation, City Council members became very quiet and were focused on what I was saying. This is how I learned that my speech impairment could actually be an asset rather than a liability. In spite of my speaking limitations, people were voicing their support and respect for my efforts to communicate. I felt truly empowered and knew I would never again remain silent when I had a message to convey.

From that experience, I gained the confidence to become active in the community and joined a local organization, Mobility on Wheels (MOW). I was not only an active member of MOW but I soon became a member of its Governing Board and eventually, President. In that capacity, I became involved in efforts to get the local bus company to purchase lift equipped coaches. The bus company believed it was only required to provide Para-transit Services (door to door van service) and it could purchase lift equipped coaches only if it chose to. The MOW membership and its Board felt that state law (under the Virginians with Disabilities Act) required the provision of both options. I agreed so strongly with this interpretation that I pursued legal action along with two others, against the bus company. Unfortunately, the judge who heard the case did not understand the significance of our case as a civil (disability) rights issue and ruled in favor of the bus

company. However, this experience made me more comfortable speaking up for my rights in both a public and legal arena. And, today, in Richmond, where I live and most major cities, the public buses are 100% lift equipped. I am extremely proud to have been part of that initiative. Public transportation has played a major role in my quest for independent living and my ability to obtain and retain employment.

From that experience, I also learned the value of working from within the legislative system. As President of Handicaps Unlimited of VA (HUVVA), a coalition of consumer advocacy groups, I learned the power of working with a variety of stakeholders to gain consensus around common issues. If you expected to persuade a busy legislator to take on your cause, you better have done your homework. I learned to be brief and to the point, because, at most, you would probably have only 10 minutes to present your case. Consensus building and the value of clear and accurate communication were the skills that I took from this experience.

Although I have been involved in dozens of systems advocacy projects throughout the years, perhaps the most exciting opportunity awaits. As the Governor's liaison to the disability community I am facing both my greatest challenge and greatest opportunity. In the past, I have concentrated much of my energy on employment issues. However, I now have the opportunity to focus on all of the areas that need attention in our communities such as housing, transportation, education, employment and inclusion in government dialogue and decision making. In Virginia we are very fortunate indeed to have an enlightened Governor and Cabinet who are sensitive to and well educated on the needs of persons with disabilities. During their tenure, I expect to see legislation and action that will affect generations to come. In the brief time I have held this position, I have already seen significant progress. We are implementing the Olmstead Initiative and expecting a favorable response on the state's Money Follows the Person grant. These are two powerful projects that will provide independent living opportunities to those who never dreamed of this possibility. Also in the works are public-private employment partnerships and programs that will assist our veterans who were wounded in their return to a successful life. I am honored to be part of this process and know that my advocacy skills will be tested as never before.

6. Summary

So, as you can see, my self-advocacy journey continues. I have gained much along the way. I know

that a self advocate never ignores a wrong when the opportunity exists to correct it. Self advocates are not afraid to reject conventional wisdom and advice when they know it is the wrong path. They are confident, take charge individuals who know that making excuses

and blaming others will take them nowhere. The path I have taken may not be the one for you or those you serve. However, self-advocacy allows all who choose it, to navigate life under their own terms.