

My Life Before and After Self-Determination

By
Brian Towles

In the, Fall of 1996, I became confined to a motorized wheelchair from a progressive disease called early onset dystonia muscular deformity that I contracted at age five. By the, Spring of 1997, I was searching for ways to get help with daily living, because my disease was progressing faster than usual, which I knew if I did not receive assistants I would be a young corpse. I started my search for help by calling different home care providers in the telephone book yellow pages, which most advertised for elderly care and/or hospice care; I knew from when my dad passed over that hospice was not what I needed, and I knew I was not old enough to be considered elderly.

In the early, Spring of 1997, I found McPherson Home Care services that in their advertisement included physically disabled, so a nurse came out to evaluate me for services, which I found out later I could not afford. I was referred to the Family Independence Agency through them I received a caseworker who helped me get assistance to help pay for the care I required from McPherson Home Care Services. Everything was going good besides staff only showing up when they felt like it. After a male staff sexually assaulted me, I took no prisoners with my verbal attacks, so McPherson Home Care Services decided to drop me like a hot potato.

In the, Fall of 1998, Community Supportive Living was the best home care provider I was ever with but like most home care providers they grew too quickly, and the quality of care began to falter by staff not showing up on time (if they

showed up at all) and by staff not knowing how to cook a frozen pizza. By this point, I was growing sick of staff not performing their job, and others complaining about picking up the slack; what could I do about people slacking off, I am not their babysitter, and if I were, the staff would not like my iron fist approach to making people pull their own weight. Nevertheless, I complained to the people in charge, but for all my complaining, nothing changed until Community Supportive Living could no longer provide home care services to their clients because of governmental rules.

In the winter of 2002, I was placed with Estuary home care provider. However, the minute they announced the company was moving toward becoming a corporation. I knew things were already starting to deteriorate by the quality of care I was receiving I realized things were going to get even worse than it all ready was; by staff not trained on basic care that I required, such as, cooking and cleaning, also knowing how to apply an external catheter. I began pushing myself to do research on how I could become my own provider in secret because I did not want Estuary to decide to drop me before I had all my ducks lined up in a neat row. During this, another staff member sexually harmed me and by the time help was offered, it was too late to file criminal charges. I received a notice in, April of 2005, stating Estuary Corporation could no longer provide me services after, May of 2005, so my caseworker got involved in assisting me in becoming my own provider.

In May of 2005, I hired friend and former Estuary employee who said if I ever became my own provider that she would leave Estuary to come work for me.

resently my friend/staff is still working for me. For the most part things have gone very well, but we work together to make things run smoothly. For example, we work around each other schedule; we do fun activities like go out to eat at actual restaurants besides fast-food joints, we visit my family more then I had with any other home care provider, we took a vacation together to see my relatives in West Virginia which would not be possible with any other home care provider. We are able to move forward, because I am now back in college earning a degree in Social work, but without her ability to work around my school schedule this would never workout. For me to return to college with any other home care agency is nearly impossible due to the simple fact they are unreliable. I enjoy my friend's children, because of the fun things they do that brighten up my day. I was with a home care agency my friend could not bring her kids to work with her, and I would not have the joy of having the sounds of children in my life. Self-determination gave me back a level of independence and freedom that I had not experienced with any providers.