

“My life as an Advocate” by David Hart, VOR Board Member The Voice * Winter 2012

I know when my parents became advocates for individuals with ID/DD. It was March 4, 1964, when their son, Christopher, my older brother was born. My father led the charge, and my mother was the support needed at home. I do not believe my father realized the depth to which his advocacy would take him, nor did he realize the impact his advocacy would have on me.

My brother suffered from Hydrocephalus, which simply is fluid on the brain that does not drain naturally, causing severe headaches and brain damage. At his best, my brother's cognitive level was no more than 12-18 months with a rudimentary vocabulary of about 20 words. Eventually, due to many physical complications of this condition, Christopher was wheelchair bound from about twelve years old.

For this article, I have been asked to offer a sibling's perspective and share when and, more importantly, why I became an advocate - first for my brother and then for all individuals with ID/DD. The *why* is simple. I firmly believe that as human beings it is our duty to help those that are less fortunate than us. The *when*? That is a little more difficult to answer, although, as with most people who are passionate advocates, I did have an “AH HA” moment.

I was attending my first Individual Service Plan (ISP) with my parents at Hogan Developmental Center in Massachusetts where my brother lived. I remember sitting in the conference room with (and I use the term loosely) “team” discussing my brother's current status. My parents and I were there to discuss the services being provided, and future services for the following year. The “team” members were telling my parents and me all the great things they did for Chris, the services he received, will receive and how happy he said he was.

Wait a minute, “how happy he *said* he was”? Not knowing if I was a full-fledged member of the “team” I was unsure if I could ask a question or make a comment. However, I did simply ask, “when did Christopher start talking?” The ISP was written in the first person and made him sound like he was a “Rhodes Scholar”. My father looked at me, smiled and shrugged knowingly, my mother groaned, (probably thinking the apple did not fall far from the tree) as we all looked at the “team”.

To most this might not be an issue, but to me I found it to be very insulting to both my family and my brother. This was my “AH HA” moment. This was the point in my life that I realized I was an advocate for not only my brother but for others with ID/DD. My father started a parents group, (now called CCMR, Inc.) at Hogan in 1976, which I am proud, to say is still advocating on behalf of people with ID/DD in Massachusetts.

As for me, I am the current President of CCMR. About ten years ago I came across VOR and realized that the fight for dignity, services, safety and equality for all with ID/DD is not only local but also national. CCMR is now a Massachusetts affiliate of VOR and I am a Board member and serve on three VOR committees.

My brother died in July of 1996, one of the most difficult and emotional times in my life and without the support of my wife Elizabeth, I could not have moved forward. I pledged then, as I do now, that I will forever in his memory advocate for people with ID/DD.