

## **Sibling's Perspective: My Advocacy Legacy**

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**VOR Board Member**

**Joyce's brother**

My sister, Joyce, who will be 57 this month, has the mind of a 2 to 2 1/2 year old child. She can't speak but does make numerous sounds that sometimes express her mood. She is currently in a community home run by Search Development in the metropolitan Chicago area. She was previously in the state operated Anne M. Kiley Developmental Center in Waukegan, Illinois.

My brother, Wayne, and I became legal guardians of Joyce in the summer of 2002 when our father, Warren, died (Violet, our mother, had passed away two summers earlier). I am the "baby" of the family and grew up realizing, of course, that Joyce was mentally retarded but, to me, she was just my sister albeit different. When we became the legal guardians, that perspective completely changed. All of a sudden, Wayne and I became the responsible ones – we had to now make all the decisions on Joyce's placement, care, etc. Watching out for Joyce was no longer our parents' "job" but ours.

Looking back, I have come to believe that our parents were trying to protect us. My parents didn't discuss the personal challenges in having a child with profound mental retardation. They rarely mentioned the numerous efforts to close or severely reduce the state support to the ICFs/MR. I only began to grasp the complexity of the issues when I joined VOR. In fact, I was only somewhat aware of the groups that my parents were active in before they died: VOR, Illinois League of Advocates for the Developmentally Disabled (IL-ADD), and the Kiley Parents group. I joined these groups after my parents were gone simply because they had been members.

As I have been involved in VOR, I have gained tremendous respect for all the parents, past and present. They were/are the ones who had to make the tough decisions as to what to do with their son or daughter – and sometimes, more than one child. As I have become older and hopefully wiser, I realize that, no matter what decision the parents of people with mental retardation made, they did a lot of second guessing subjecting themselves to needless guilt as to whether they were making the right choices. And, as we all know, back in the 50's and 60's, there weren't always good choices and certainly not easy ones.

I would like to urge today's parents (or siblings) to talk with their children (or other siblings) about what challenges we all face to ensure that our loved ones have safe caring environments in which they can thrive as best as possible. Let them know about the good work that VOR does along with the local and state groups. While they may not be able to be active in these groups depending on their other responsibilities and stage in life, your loved ones could maintain an awareness of the challenges that are out there through membership and keeping informed. Finally, the most important thing you can do is talk to your children or other siblings. Keep them aware of the challenges you face and, perhaps, even your fears.

