

## Sibling Perspective

By Saskia Davis

I'd like you to meet my sister, Kathy. Here she is with a housemate and Pickles, the dog in their living room at Fircrest, enjoying a game of "hat". It used to be that hats and rides were her favorite things in the world, followed closely by treats. Recently, we have had the pleasure of adding dogs to that list.

Fircrest has been Kathy's home for 48 years. As one of Washington State's Residential Habilitation Centers (RHCs), Fircrest has separate licensing as an ICF/MR and a nursing facility. With cerebral palsy, mental age of about 2.5 years, bipolar disease, epilepsy and osteopenia, Kathy is best served in Fircrest's nursing facility. Licensing of Washington's RHCs varies: ICF/MR, NF, or dual. They are incredible resources.



Considering the road that Kathy and I have traveled together to where she is now, at Fircrest, I am thankful every day for all of her compassionate care and the friendships she has developed at her home.

Growing up, I spent every spare moment taking care of Kathy. I would do it all over again for her, though I would change some things. First, caring for Kathy at home was very difficult on my family. Some subsidy for services would have helped. According to the doctors, Kathy was to be a "vegetable," but our mother stubbornly "doctor-shopped" until she found a resourceful doctor. After surgery at age 13 months, Kathy came alive, and with therapy plus our 24-7 support, she blossomed, slowly mastering basic toddler skills, despite her severe cerebral palsy. The trade-off for me was that I didn't/couldn't have much of a social life or have time for after-school activities. For our parents the load was huge between caregiving and making ends meet in view of uninsured medical and therapy costs. Ultimately, the stresses took their toll. Our parents ended up apart; and then our father died.

Knowing a bit about the beginning of our journey, and then, the wonderful support that Kathy has now, perhaps you can see why I am dedicated to ensuring that Washington State RHCs remain an option for Kathy and her peers across the state. The facility closures plus the cuts now being implemented to all-services for disabled people in our state risk not only forcing Kathy from her home, but also will hurt younger families who are still caring for their loved ones at home. I really fear that the cuts will bring upon those younger families the same challenges Kathy and I and our parents faced so many years ago.

And that's why I advocate. I am absolutely motivated by what I know to be in my sister's best interest. In this way, my sibling "point of view" is not that different from other RHC family advocates. We're all motivated by our love for our family member and are secure in the fact we know what's necessary for their happiness and protection. Most of us can remember the time when we had to face that we no longer could meet their needs at home. Most of us also tried "community" until that didn't work anymore, and we know the initial heartbreak and ultimate salvation that "institutions" (RHCs) represent. We all also collectively rejoice in the improvements we've seen, thanks to Medicaid, over the years. Federal funding and annual inspections ensure continual high quality, humane care. All of the people at Fircrest have a life where their conditions are managed in such a way that they can participate in daily activities: personal empowerment program, jobs, school and recreation, on and off campus.

While Kathy must be my priority, I also want to help as many as possible to have the resources they need; and I believe through sharing, we can find the answers we need. To those ends, I host the Developmental Disabilities Exchange at <http://ddexchange.blogspot.com/>. Please visit. I'd love to exchange ideas with you.