

Testimony of Paul Heyn

Ladies and Gentleman,

Thank you for inviting me here today. I have two adult children. Debbie, 41 and Steve 39 both of whom have Huntington's Disease. This is a neurological disease that slowly effects both the mind and body. With this disease there is a 50/50 chance of getting it, unfortunately both of my children have the disease that they inherited from their mother and have had it for about 12 years. My wife had the disease and died at the age of 57, eleven years ago. She was at Napa State Hospital for twenty seven years at the expense of the state government because they didn't have Adult Day Health Care (ADHC) or In-Home Support Services (IHSS) in those days. I also lost a daughter at 29 days of age because of a genetic disorder.

Steve and Debbie have been going to ADHC for about 2 ½ years. They went to Robertson's Adult Day Care for over 2 years but it was closed several months ago because of financial problems due to regulatory factors and because of budget reasons by the state.

We along with the employees were given a 1-day notice along of the closure. After several weeks our social worker was able to get us into Ranch Cordova Adult Day Care.

I was so happy because I could see the difference in my children in that short amount of time. Before attending the Rancho Cordova facility they seemed depressed as they missed the scheduling and interaction with people at the center. They also lost weight which is a real problem with this disease. My wife had a feeding tube for 20 years in order to keep her weight up.

So we are happy once again as they are doing so much better. They are picked up at 7:00 am and are home around 2:00pm, of this, over 2 hours is transportation time. They get a good breakfast when they arrive at the center. Someone at the center feeds them by hand and gives them their drinks, something they can't do for themselves anymore. They are taken to the bathroom every 2 hours as they have little control over their bladder and bowels.

Lunch is at 12:00pm. They are given their medications and a nutritional drink by the nurses at that time. They have activities such as singing, storytelling, games, crafts, movies, exercise and gardening.

The interaction is a wonderful thing for them as the only thing they are able to do at home anymore is watch TV, everything else I or my in-home support person does for them.

While they are at the center I am able to do the necessary things that have to be done. I work as a janitor for my church school for about 4 hours, 5 days a week in order to make ends meet financially. I have been doing this since my retirement at 62 years old. I am now 70 years old.

Debbie's daughter is also living with us. I have taken care of her since she was a baby. She is 19 and is studying to be a nurse, and wants to work with the disabled. As you know college costs are very expensive, so with my job I can help her with her expenses.

If the ADHC's are closed I would have to quit my job and she would probably have to stop going to college and help with the care of her mother and uncle.

While they're at the center I do the grocery shopping as well as any other shopping that has to be done. I do laundry, vacuum, clean the house, cook supper, make doctor visits, pickup medications and prepare them, take care of the finances and pay bills for 4 people.

I try to make time for reading the paper and the Bible; we are unable to go to church because of this disease.

I have 1 acre of land so I have to cut the grass and all the other yard work. However; this is one part of my responsibility I love to do in my so called retirement.

Please do all you can to keep the ADHC's open, so that my family and so many other families of the disabled and aging will be able to have some kind of normal life for themselves.

The closures will affect so many loving and caring patients and employees at these facilities as well. They are the best of the best.

Sincerely,

Paul Heyn