



Lifesharing

**“What a Difference A Home Makes”
An Interview with Nancy and
Elizabeth of Mercersburg, PA**

Lifesharing, also known as “Family Living” (55 PA Code Chapter 6500), officially began in Pennsylvania in 1982 with a family in Berks County who wanted to support their friend in their own home. To reflect the diversity of relationships in these living arrangements, “Family Living” became best known as *Lifesharing* to better describe the lifestyles and choices. Today 1,909 individuals live in family living homes, also referred to as Lifesharing through Family Living homes.

Q: *Why did you decide to become involved in Lifesharing?*

R: In 1976 I worked and lived with people with disabilities in a group home in Maryland. At that time we were called “houseparents” and lived in the home for ten consecutive days and nights, then four days away, creating more family-like relationships. Over time I moved into several administrative roles and was fortunate to have wonderful teachers and mentors along the way. At one point I lived with three teenagers with “behavior problems”. That’s when I was introduced to the teachings of Jean Vanier, founder of L’Arche Communities. L’Arche began in France in 1964 bringing together those with disabilities and those without to live

together in community. While attending a L’Arche retreat in August 1985, I had a ten-minute conversation with Jean Vanier. Not knowing my background, other than my concerns for people moving from institutions, his question to me was “Why do you live alone?” Now I see this question as my calling. In 1989, I decided to offer my home to a person with a disability. I abandoned the futility of trying to make life better for everyone, and would try to make life the best I could for one person.

Q: *How did Elizabeth come to be part of your family?*

R: I had moved to Pennsylvania and contacted the local ARC, who put me in touch with an agency. Elizabeth was one of their clients. Elizabeth had left her family at three years of age, and when I met her she was seven and had already lived with three other families. In June of 1989, her parents brought her for a visit to my home, along with her younger brother and sister. During their visit, her parents asked if I wanted to hold Elizabeth and they gave us a few minutes of privacy. Elizabeth was not able to communicate with words or walk, but when I held her, she looked at me and made happy “singing” sounds. I took this as a message that Elizabeth wanted to give me a try.

Q: *Tell us a little bit about Elizabeth. Who is she?*

R: What most people notice first about Elizabeth is her beauty. When we are out in the community people seem drawn to her, and usually come and tell us something about themselves. I believe this, including her disabilities, is her vocation. At the hairdresser today, a woman talked to Elizabeth, but Elizabeth was looking at the lights. When we were ready to leave I brought Elizabeth closer to the woman and Elizabeth looked right into her eyes.

The woman gave her a kiss on her cheek. I know she was touched by, and will remember Elizabeth. This is Elizabeth's gift she has to give people.

Elizabeth also loves trees, She understand their language. When we go places the trees are her landmarks. Elizabeth doesn't feel sorry for herself, and she can't be bribed. Her language is different than what most people think or know. It takes time to listen to her sounds, watch her mannerisms, and learn her language. She loves live instrumental music and sopranos. This past year her music therapy was not funded, which is a disappointment. Elizabeth is not a copy of you, minus what she can't do that you can; she is so much more.

Q: *How is your life different since Elizabeth has become part of your family?*

R: Both of us had to change. Elizabeth had a lot of sensory problems. She could not be around noise, would not let people touch her, and couldn't even touch herself. She cried most of the time she was awake. She spent many hours sitting at the front door looking at the trees. Her sensory problems had been misdiagnosed as behavior problems. We both had to stay home most of the time, and even grocery shopping was difficult. Now it is such a joy for her to relax in my lap. Everyday we save her life, and I believe, mine.

Things we do have to be things we both can do. We spend a lot of time on the floor, it is the place where Elizabeth is safe and has more freedom of movement. We use the wheelchair outdoors, not in our house. We have a tandem tricycle, our "dream machine" that we enjoy riding. We live in a rural area and during the summer we ride often. Sometimes we take the "dream machine" to Rails-to-Trails. These

activities are things that developed slowly over time.

Q: *Who do you go to when you need support?*

R: I have some friends I can talk with. My life is quite different from most people. My sister often joins us for outings. Elizabeth's family is supportive in many ways. People at the Lifesharing Subcommittee have been invaluable. The Subcommittee is a place where I can find out that what I am thinking is not off the wall. It is a great place to learn about best practices.

Q: *What is your best memory together since becoming a family?*

R: Our best times are having a simple picnic and relaxing among the trees. In 1994, we took a trip to Maine for a Lifesharing Reunion. Over the weekend we walked to a lighthouse, rode a lobster boat, heard bagpipes, collected beach rocks, and ate lobster as part of the reunion. We extended it to a ten-day "road trip". We had a remarkable experience at this year's Lifesharing Reunion. I can push Elizabeth's wheelchair on unpaved roads so we decided to get out and do the scheduled hike. I found out quickly it was a difficult, steep terrain, with tree roots and rocks. Gradually people started to help us, more and more joined in, at times requiring five at a time. They took turns as people tired. At first I was apologizing, but they assured me it was as meaningful for them as it was for Elizabeth. The River Gorge was such a beautiful, unspoiled place, where we never would have been without their help.

Q: *How is Elizabeth's family involved in her life?*

R: Elizabeth's parent's live less than ten miles away. She spends one weekend and one Sunday afternoon a month with them. I don't always make it easy for them because of things I try to

advocate for Elizabeth and myself, but they have gone to bat for me many times. They appreciate our relationship and companionship. At Christmas time we all marveled at how long we've been together.

Q: *What new experiences are in store for you and Elizabeth in the future?*

R: Elizabeth has eating problems, and anorexia. I spend about half of the day feeding her. If her eating could level off, it would change our lives tremendously. Elizabeth is a wonderful teacher. Because of her I learned the Feldenkrais Method, which helps to increase human functioning by movement and awareness. Remarkably, it improved her scoliosis so it is no longer a threat, and also helped with her sensory problems. I have become a practitioner and we would love to have people come to our home for wellness retreats so that we could share what we have learned. And, like most people, we would love to travel more.

Q: *How has Elizabeth developed friendships outside of your family?*

R: Most of Elizabeth's friendships are with neighbors and people we know in common. Elizabeth went to a segregated school, so natural school friendships did not happen. I have noticed that in the past year when we go out, more people say hello to her. I think this is because she looks at people more directly now. Before, she either looked at a far distance or close up, but never in that in-between space where people usually travel. I've also noticed that she looks at boys more often.

Q: *What lessons have you learned about lifesharing that you would like to share with others?*

R: Make one person's life as good as you can, and by doing that it will spill over and help many other people. In trying to speak for ourselves, we have

helped other people. Despite our struggles, life has gotten better for both of us. If you are involved in Lifesharing, use the Lifesharing Subcommittee for support. The power of Lifesharing is in relationships.

*Interviewed by Dorothy Minnick, Feature
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