



Sibling's Perspective - My Sister Lauren

By Linda Lotzi, VOR Board Member

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In 1998, I became the primary contact and the court appointed personal guardian of my sister, Lauren. Lauren's home for the last 41 years has been White Haven Center (WHC), an Intermediate Care Facility (ICF/MR) in Pennsylvania. Our parents wished for Lauren to reside at White Haven as long as she is safe and happy.

Since I was young, I have experienced what it is like to have a sister with severe profound intellectual disabilities. I felt the struggles my parents had with Lauren when we were young. I remember many times when Lauren would fall to the floor and have a seizure. I was only five years old. I remember how hard it was on our family when Lauren was brought to White Haven Center to live. I was very sad and did not understand. Back then there were no supports in place to help family's keep their loved one home. Society dictated then that facilities were the best way to support a family with a child that has disabilities. Today, forty years later, society is still trying to dictate what is best for my sister and her friends. Has society seen her home? Do they care and know what will happen to my sister if she is removed from her home? Once, when White Haven planned to move her from one building to another, she stopped eating. Care and attention by family and staff helped her feel comfortable and eventually she accepted food. Will community staff be as patient or trained? I fear she will stop eating again and the "community" solution will be a feeding tube.

Like nearly all her peers at White Haven, Lauren's disabilities and needs are significant. She has severe intellectual disabilities due to corticocerebellar damage and prenatal hyposia, fibrocystic breast disease-bilateral, a seizure disorder, degenerative osteoarthritis of the spine, spastic quadriplegia, and more. Lauren is non-communicative and non-ambulatory. She has been blessed with a loving staff that cares about her and her friends and knows her very well. They have devoted decades of service and are highly skilled in providing care to WHC residents.

A Protection & Advocacy lawsuit threatens WHC and other centers. We are grateful for the attorneys who have been helping the families object and I'm grateful to VOR for participating as Amicus. We are fighting hard for Lauren's friends who have no other voice. Given the freedom, safety and services that Lauren and her friends have at White Haven Center, it is our belief that White Haven Center is the least restrictive environment to meet her needs and a community residential setting would be more restrictive. I'm so grateful to have found VOR a little more than a year ago and honored to be participating as a board member. I won't stop fighting for my sister Lauren.