

Holding Space ...

Dear Friends of The Arc Carroll County,

I knew I would lose the argument the minute it started. "I am moving back to Maryland next month," said my mother, almost flatly ... like she was announcing changing car insurance companies.

My mother and I had very few arguments during her lifetime, but I had enough experience to know that this was one I would lose before even starting. Already retired as a psychiatric social worker for the state of South Carolina, she had pondered when and how to return to Westminster. After her aunt, the sole surviving matriarch in the family, had to be placed in a nursing home, the family home at 130 E. Main sat empty and calling to her to return. It had always been my mother's dream to spend her remaining days in the home she grew up in. With Aunt Louise's having to leave it, she seized the moment. To be clear, my conflict wasn't about my mother's dream as much as it was about what was in her daughter's, and my sister's, best interests.

"What about Lulu," I asked. Lulu, my twin sister, was born with Down syndrome and, consistent with the general medical advice in the early 1960s, institutionalized in a state facility at approximately two years of age. As the trend to de-institutionalizing grew, by the time I graduated high school she was living in a group home with seven other residents in *the* model group home in terms of facilities, milieu and staffing, and was one of the most sought-after placements in South Carolina. Lulu was thriving.

My mother replied, "She is going to live in the house with me." I knew how this would go. My aging mother did not have the energy or ability to provide the socialization that Lulu needed to maintain her level of functioning, which among kids with Down syndrome was pretty high. And sure enough, within months after pulling her from her existing structure, support, and quality of the life, Lulu declined. She became less verbal, gained weight, developed obsessive-compulsive traits and was depressed.

I clearly and firmly confronted my mother with my sister's decline, which was hard to miss so there wasn't much room for argument. Much to my mother's credit, the next week she reached out to The Arc Carroll County.

Immediately Lulu's needs were met. After an assessment of her needs, she began working as a dishwasher at her favorite pizza restaurant. The job gave her life structure, socialization and fun. She was in her environment ... she loved people and people loved her, and she was being productive. And she was near pizza, which is a good gig when food is one of your great loves. Lulu came back to life. Her depression lifted, her social skills returned, she lost some weight and her obsessive compulsive traits diminished.



After seeing everything good that came from the changes in Lulu's life, and again to her credit, my mother began thinking long term and realized she needed to think about plans for Lulu after her death. She placed Lulu on a waiting list with The Arc for a bed, although the list was years long.



A few years later, our mother had a seizure that resulted in a bad fall. Hospitalized for weeks, Lulu immediately became eligible for emergency placement. The Arc immediately arranged placement for Lulu, which included for a short time even having her live temporarily in the homes of several staff people until a bed opened for her at Monocacy, the residence that would become her home for the rest of her life.

Our mother's health never returned to the point that she could live independently, and it appeared that she might continue to live for a number of years, so I approached The Arc about finding placement for Lulu with me in Kentucky, which had been my home for most of my adult life.



Kentucky's residential waiting list was about 10-12 years long. I called Mary Jo Walla, of The Arc, to have a conversation about a plan for Lulu. I was distraught and anxious as I dialed the phone because I did not see an easy or clear way forward. I explained Kentucky's waiting list to Mary Jo. I will never forget her response:

*"Ben, by the time a bed opens up for Lulu, she will be in her sixties. To ask her to make such a dramatic adjustment would easily overwhelm her to the point that she might never recover and she could even die. **Leave her here with us. We love her. She has a home here and we will take good care of her.**"*

The Arc held space for my sister for the rest of her life, including during her long and slow decline from Alzheimer's, but more importantly, they **held space in their hearts for my sister from the time they met her until the time she died.**

Please donate to The Arc's Annual Fund today, knowing that your tax-deductible gift will make a difference in the lives of people with intellectual and developmental disabilities.

Sincerely,

Ben Wyman