

Guardianship: One Family's Perspective

By Terri Hancock

The recent news about the passing of President George H. W. Bush. It made me think about the legislation that has helped people with disabilities live a free life in the community. The Rehabilitation Act was created in 1973, the Americans with Disabilities Act in 1990, and the Individuals with Disabilities Education Act in 1975. Yet, in 2018 we still have very low employment for people with disabilities, inaccessible buildings, not enough accessible parking, and children are still segregated in classrooms in schools. Added to this slow progress is the unfortunate fact that the number of people in guardianship has tripled in the last 20 years.

We still think that everyone needs to be kept safe and that it is our job to do so. People with disabilities are not given the dignity of risk, and the opportunities to learn from their choices and actions that comes with the chance to have a breadth of experience. Instead of empowering people we take everything away from them. How are they going to recognize danger when they see it? Do we think that guardianship is going to keep them safe? The more power someone has over someone else and the more segregated that person is, the higher the chance is for abuse.

My daughter Brigitte was born 31 years ago in a hospital that was not ready for her into a world that had a lot to learn about children with disabilities. And of course, to parents who were not expecting the baby that was handed to them. It's a very tough road for parents. You are given so much advice. I wish now that someone would have just said to me "treat her like your other kids. She will not do some things and other things she will do differently. She will be her own person. She needs all of the opportunities and experiences your other kids have." I would have learned much earlier than I did, that what we really want-and what Brigitte wants- is for Brigitte to be the best Brigitte she can be. Her disability is not who she is but it is a big part of her life and she should wear it proudly. It's a tough climb to adulthood, especially when you are told over and over again that you will never get there.

Brigitte has cerebral palsy. It happened a little bit at a time. Lack of oxygen at birth led to developmental delays. But she could walk holding onto furniture, roll all over the floor and her language was above average. At age 20 months she had a grand mal seizure. The seizure lasted for over an hour and she was put into a coma to calm her seizure activity down. For the second time in her short life she received brain damage from lack of oxygen. Two weeks later we brought a different child home with us. She did not know us, she could no longer speak and her mobility went back to infancy. She has made some small gains over the years but has never regained what she lost. We mourned the child we lost and fell in love with the new child we brought home. Over the years we have seen glimpses of the first child and realize that she is still there. There is quite a wonderful young lady in there. She has been communicating all along. We just needed to take the time to listen.

It was in early intervention that we were told there was a "special" school for Brigitte where she would thrive. Here is where the advice of treating her just like your other kids would have come in handy. It was a wonderful school as far as offering caring teachers and paraprofessionals, therapies, equipment, and state of the art technology. She would be "safe" there. Brigitte was very social, always smiling and laughing. While other kids took naps, she was put in the hallway so that she could be a part of the hustle and bustle and people would stop and talk with her. Brigitte didn't speak but she did want to be a part of the crowd. If I had it to do over, Brigitte would have attended her neighborhood school and I would advocate for the kinds of things that she needed and were provided as a matter of course in her special school. I wasn't listening to Brigitte. Luckily, the school was. They saw her personality and love of people. They wanted to integrate her into another school. I was too afraid. I worried that she wouldn't

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be "safe". My fears for Brigitte and my inability to let her take a risk held her back from the school life she should have had.

When Brigitte was older and out of school I worked for the Center for Disabilities Studies at the University of Delaware for five years. During that time I asked as a favor if Brigitte could attend a semester in the Disabilities Minor (the largest minor at UD). Because I had friends there they agreed to let Brigitte into the class to audit. There were many questions such as what to do if Brigitte had a seizure. My answer was to call 911, because that's what one would do for any other student. Brigitte very much enjoyed me dropping her off for an hour and 15 minutes twice a week. But it's possible that I learned the greatest lessons through this experience. The first day I brought her in to class, one of the students moved her chair over to make room for Brigitte's wheelchair. I introduced Brigitte and left. When I came back there were papers on the tray of Brigitte's wheelchair. Not thinking about it, and knowing Brigitte had little use for reading material, I moved the papers to a nearby table and proceeded to leave with Brigitte. The student who sat next to her in class ran after me and handed me the papers. She said "Brigitte forgot these." I didn't see the importance of Brigitte having those papers like the rest of the class but that student did.

When Brigitte turned 18, I was told at her IEP meeting that, as her parents, we should seek guardianship. There were no other options offered. We were told that if we did not acquire guardianship and something happened to Brigitte, for example she needed surgery, we could not sign. This was not true. As in most states, in Delaware if someone is incapacitated the next of kin can make decisions. We could have made decisions as her mother and father without becoming Brigitte's legal guardians, but we didn't know any better. The school truly believed that guardianship was necessary and many, along with the medical community and courts, still do.

I read about how to acquire guardianship on our own. It was only \$240 and we acted as our own attorney. Brigitte was appointed an attorney through the courts. The attorney came to our home, spent 10 minutes with Brigitte, talked to us and ruled that Brigitte was incompetent. It was very simple to get guardianship of Brigitte. It should not have been that easy. Brigitte never went before a judge. They took the word of her parents (who thought they were doing both the right and required thing) and a lawyer who had spent 10 minutes with Brigitte. The thing is, Brigitte is not a person you can get to know in just a few minutes. Brigitte doesn't speak but she is full of ideas and opinions. She is an amazing communicator but she communicates with expressions and gestures; you have to know her to be able to listen.

Sadly, and without it being our intent, the day we were granted guardianship of Brigitte was the day Brigitte was no longer considered a "real" person. Once we acquired guardianship her signature (whether it be an x or a swipe of the pen) meant nothing. None of her decisions were her own. When we realized our mistake we wrote to the courts and were told that guardianship is generally irrevocable. In order to reverse the decision we had made with good intent but mistakenly, we would have to prove that Brigitte had "completely recovered"; clearly, this was never going to be the case.

I remember an incident that drove home to me the error we had made when we became Brigitte's guardians. I took Brigitte to the bank one day to get her own ATM card. It was important to us that Brigitte have her own card with her name on it in her backpack on the back of her chair. Brigitte and I rolled up to the desk at the bank and told them that Brigitte needed her own account and her own card. The woman asked if I had guardianship. When I said yes, she said well then Brigitte can not have

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anything in her name. Further, the woman at the bank told me that Brigitte would need to have permission from the court to take any money out of an account. I cried all the way home. I thought, in our desire to do the right thing, we had taken everything from Brigitte. I called the Court just to make sure. I was told that we had not filed for financial guardianship, but rather for "guardianship of self". So Brigitte **could** have her own account and card. I drove Brigitte back to the bank, helped her sign the papers hand- over- hand and she now has her own account and ATM card. That's a big deal for her. It's a symbol of her independence.

In 2016 Delaware passed legislation that allowed for Supported Decision Making. In Supported Decision Making a person still retains all of his/her rights to make decisions but the person can have support in making decisions as needed or desired. That support may be in the form of someone going to the doctors with them and breaking down the information so that the person can better understand what the physician is talking about. It may be some help with finances or with understanding and making any kind of complicated decisions. Delaware's Supported Decision Making law and application can be found here at https://dhss.delaware.gov/dsaapd/files/supported_decision_making_information.pdf.

Supported Decision Making is the least restrictive option in Delaware, Guardianship is the most restrictive. A few weeks ago we filed papers with the Chancery Court to remove Brigitte from guardianship and also submitted a form to acquire Surrogate Decision Making. Because we knew we couldn't prove that Brigitte had or would 'completely recover' from her lifelong disability, we knew the courts would not let us end guardianship without having something in it's place. The courts worked on a new rule that allowed termination of guardianship for a less restrictive form of decision making. Surrogate Decision Making lets us make Brigitte's healthcare decisions but does not take away any of Brigitte's other rights or decision-making authority. Just last week we received the news that our Petition to Terminate Guardianship had been granted! It is wonderful that there are now more options. Parents need to understand all the options and the long ranging ramifications of becoming a guardian. In many states people who have a guardian can't even vote! There is need to educate parents and caregivers, school personnel, the medical community, financial institutions and courts. We have a lot of work to do.

Ten years before Brigitte graduated from school with a (certificate of attendance), I, along with her principal and a few others founded a day program. The day program based on the same model as the special school. It was segregated, Brigitte spent all day with people just like her; people who didn't walk and couldn't speak. Again I was trying to make sure that she was safe. When Brigitte left school at age 21 she went right into the program that I had helped create. She lasted less than a year. She was very bored and I saw that when she came home with her shirts chewed up and her hair wet from chewing on it. It took me 21 years to realize the gift of community and how I had held Brigitte back by segregating her. Brigitte's former principal and I created a program at our local YMCA that will be in every Y in Delaware soon. It is called Endless Possibilities In the Community. https://youtu.be/1eT2N_1VSI0. People with disabilities are paired one on one with a student from the University of Delaware Behavioral Health and Nutrition or Exercise Science Departments. That student works with the person who has a disability to use exercise equipment and all the resources of the Y. They spend 3 hours at the Y doing the workout that they choose, swimming, and participating in classes and social opportunities. We are very careful to only have 6 people who are part of the program at the Y at a time. This assures that they are not in a disability program but interacting with the community members who also go to the Y. The people with disabilities who are part of the Endless Possibilities Program go to different parts of the gym

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and work out beside other members. The Y gives them a free membership and we assist with transportation as needed. We also have physical therapists at the Y for people like Brigitte who have more intense physical needs. Brigitte has become a real member of the Y, spending time in Zumba class, chair yoga, and just being part of her community.

Brigitte spends some of her time at meetings being an advocate, both locally and in Washington DC. All of the legislators in Delaware know her. She may not speak but if she is not sitting at the table, who is going to advocate for her? People need to know she is here. She did not die in her teens like the doctors predicted. We were told that she would be unable to communicate, which anyone who knows Brigitte can assure you is certainly not the case -she is able to make her own decisions and fight for them. We, like all parents have made some mistakes along the way-all with the best intentions. Becoming Brigitte's guardian was one of those mistakes but we and Brigitte are delighted that we have been successful in removing Brigitte from guardianship so she will once again be a fully legal, "real person".