



Parent Caregiver: An ‘Every Minute of Every Day’ Experience

A Conversation with Kathy, mom and caregiver of her profoundly developmentally disabled son Owen

1. Tell us about your role as a mother and caregiver.

As a parent it is expected that you will take care of your child. For a parent caring for a child with special needs, that holds true but the difference is it can be an ‘every minute of every day’ experience.

Our son Owen is profoundly developmentally disabled both physically and cognitively, which means he does not walk or talk and requires total care. My role as a parent caregiver has changed over the years. I was my son’s primary caregiver from birth to 11 years old. At that time he became eligible for personal care attendant services, which was the start of people joining our family on and off over the years. When Owen was 15 years old, there was a need to do a major renovation to the house in order to accommodate Owen’s needs for a bedroom and bathroom on the first floor. This was an expense for which we had not planned. Carrying him up and down the stairs to the second floor bedroom and bathroom had become dangerous. This renovation allowed Owen to continue to live safely at home with us.

Parent caregivers wear many hats and usually become very strong advocates for their children. You learn a lot about legal rights and guardianship, rights to medications and treatments, and accessing state and government funding and services. We are often put in a defensive position to prove the need for the simplest of services despite the obvious need. It can be physically and emotionally demanding, and at times quite overwhelming. It can also put a significant strain on family members as well. However there are many blessings, one of which for us was being a little more mindful of how we work together as a family.

2. What made your role as a parent caregiver more challenging?

As a caregiver, you interact with many doctors, specialist, and care assistants. I think the hardest part is when professionals look at a profoundly disabled young adult and only see the clinician condition. As a result, sometimes medications and treatments are started without adequately explaining the short and long side effects. It can be very scary as a mom to not understand what is going on, as some serious medications can take weeks to level out. I learned to always ask about side effects, because I was not automatically told.



It really helps the process if professionals start with the understanding that Owen is a person, that he has a family and that family loves him, and that our conversations should be about a person and not a condition. I think too if I had one wish over the years it would be that more doctors would have read the medical record prior to seeing us and didn't ask me recount the birth story over and over. It's all in the record and doesn't have much bearing on the present. When a doctor had read the record, it was enormously supportive and you felt like you were both on the same page.

3. What did you find supportive to your role as a parent caregiver?

Doctors who treated us as a family and focused on the positive were very helpful. We appreciated care providers who were truthful and not afraid to talk about what's coming down the road. I think for parents who are just starting out, it's important to tell the truth, but accentuate the positive and always offer hope.

A huge help is the other parents in the disability community who come together to provide a vital and supportive network. I remember an inside joke among parents that you sometimes felt like you joined a club you really didn't want to be a member of. But the truth is I found parents to be incredibly generous sharing knowledge and resources, and very strong supporters of each other. As services have grown over the years, parent caregivers now have the added strength of being "consumers" to choose appropriate services. Our collective voice can be very powerful for needed legislation and affordable services.

Some resources I found helpful include the Federation for Children with Special Needs, <http://fcsn.org/>, and Mass Family Voices <http://fcsn.org/mfv/>. Also Family Support funding from the Massachusetts Department of Developmental Services was a crucial factor in our being able to continue to care for Owen at home until he was 30 years old. It's important to mention that parent caregivers must find time to take care of themselves. A resource I found helpful is Lifespan Respite in Mass. <http://massrespite.org/>

4. How has your experience enabled you to help other parent caregivers?

My son Owen is now 32 and receiving full time care in a state-funded residential program very near our home. I work as a Family Liaison in the Boston Public Schools helping students who have profound disabilities and are considered medically fragile and complex. We work with families to orient them to school and help them with their journey in taking care of their kids, connecting them to both resources to which they are entitled as well as some private resources. Most importantly we connect them to each other for support and information sharing. One of the most important messages I might give a parent is to know there are parents who have walked this road before you and felt supported by other parents. We invite them to not hide at home and feel isolated, but be part of a movement of people advocating for the best care and services for their child and family.