

Roots of Resilience: by mom: Ann Donogue Dillon, M.Ed, OTR/L, published in the Worcester Medicine Journal, Jan./Feb.2014

As a child growing up in Worcester many years ago, some early experiences with disabilities ~ right in my own neighborhood and local church ~ began to shape my beliefs and values. Seeing a young man with disabilities at worship or playing with neighbors who had some differences, we didn't know the "labels," and it didn't really matter. My mother often substitute taught in a "special" school in Worcester, bringing home warm and fulfilled stories that became part of my personal history and my roots in understanding disabilities.

Eventually, going to college, becoming a pediatric occupational therapist and working in the Worcester area for many years allowed me insights and valuable life lessons. Families welcomed me into their homes to offer support, whether to an infant discharged from the hospital with risks for developmental concerns or a child experiencing a known disability. They taught me about the importance of finding strengths, creating hopeful and positive lives for their children and working with what was reality in the context of each unique family. Little did I know that they were not only teaching me how to become a better professional but were preparing me to become a mother.

When my daughter, Brie, was born in 1985, life changed quite unexpectedly. We learned in the hospital that she had a rare syndrome, would have many medical and developmental problems, and would die before the age of 2. With all my years of experiences and training, nothing prepared me for the deep and gut-wrenching news that we would lose our beautiful baby. In a strange shift in perspective, the disabilities didn't matter so much, but the thought of losing her was devastating and took up so much space in our thoughts and hearts. That loss of hope stopped us from looking forward to a life with her in our little family.

But Brie was amazing. In spite of the prevailing opinions, she grew and developed! Yes, even with many challenges (feeding tube, wheelchair, surgeries, seizures, illnesses, etc.) as part of her daily life, she went to the local school, was in regular classes, rode the regular school bus, became a Girl Scout, made her first communion, graduated from high school and even took some college classes. She taught so many people about resilience, living a normal life and being part of a community. When she passed away at age 25 several years ago, we got letters from friends and old classmates affirming what a great teacher she had been.

How did her life change me? The biggest change was about developing resilience. Looking back to my history and life experiences, adding in the present reality of what and who we had to support us, and coming up with a mindset and plan to get what we needed to move forward ~ those are all the things that helped me become more resilient, even to this day.

I really began to get my hope back and feel stronger when Brie was 3 years old. I attended a leadership training series for parents who also had children with disabilities in my new home state of New Hampshire. I began to understand that what we wanted for Brie was for her to be treated like our two other children, to have all the normal and typical life events, to be a part of everything our family and community offered. To be set apart and treated differently would be to deny her what we felt was just and fair. These realizations were the turning point in getting Brie to move from “special” to “regular,” even if that meant we didn’t have a perfectly formed plan!

Brie had a good life because we followed the path most traveled, a path that seemed closed at the beginning but one that opened up to us as we explored and strengthened our values and beliefs. We continually asked the question “What would she be doing if she didn’t have a disability?”

So now, I try to teach some of what I have learned on this journey. I teach others about how to find their own strengths and resilience. I work with different teams to best convey the essence of what leadership is and what they need to do to become stronger. In the New Hampshire Leadership Series, we help parents and individuals who have a disability to develop their leadership skills. In the New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, one of 43 in the nation, I provide a family perspective in the seminar and mentor trainees who are also parents in becoming leaders in the field. I edit for the New Hampshire Institute On Disability’s Genetics Education Material for School Success (GEMSS) website so that readers will find the educational information more parent and teacher-friendly.

My favorite questions to our aspiring leaders are:

What do you stand for?
What is keeping you from doing more?

They are questions that I even keep asking myself, and they can challenge us all to keep growing and looking for more and better ways to be involved!

Certain highlights rise to the top in the lessons learned along the way:

- Inclusion is a great beacon, the best starting point!
- Everyone needs a voice. Be their champion and help them find it!
- Rekindle hope after a developmental diagnosis.
- Believe that the child is right, whole, perfect. The “Disability is Natural” work by Kathy Snow provides some great insights.
- Assume competence, even if you haven’t heard their voice

yet.

• Independence needs to start early ~ aide and then fade in education, home, etc.

• Look for partners in medical, educational and spiritual communities ~ an ally, a reliable sounding board and honest reflectors.

Even though Brie's life on earth is over, her influence remains strong. A former third-grade classmate of Brie's, now an adult, told her nurse that she wanted a "life like Brie Dillon's" for her son, who experiences disabilities. Her roots have spread far and wide, and I am forever changed for being part of the journey!

Resources:

1. *Institute on Disability, University of New Hampshire, iod.unh.edu*

2. *NH Leadership Series, nhleadership.org*

3. *NH Leadership Education in Neurodevelopmental and Related Disabilities (LEND), mchlend.unh.edu/home.aspx*

4. *Genetics Education Material for School Success (GEMSS), gemssforschools.org*

5. *For Massachusetts Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs,*

6. *umassmed.edu/shriver and <http://www.childrenshospital.org/ici>*

7. *For Leadership opportunities for parents in Massachusetts, mfofc.org/events/fls/2014-northeast-and-metro-boston.pdf*

Ann Donoghue Dillon, M.Ed., OTR/L, is a clinical assistant professor at the Institute on Disability, University of New Hampshire.

She is coordinator of the New Hampshire Leadership Series, on the faculty of the New Hampshire LEND Program and contributor to the GEMSS Project. She is currently serving on the New Hampshire Governor's Commission on Disabilities. She formerly worked in the Child Development Services at University of Massachusetts Medical Center.