

Elizabeth Milizia
2304 Brand Farm Drive
South Burlington, VT 05403
(802)373-8983
bmilizia@comcast.net

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My name is Elizabeth “Betty” Milizia. I’m known to look for quotes that sum up in a few words, what can take me many more words to describe. Today, I will do both.

“Yankee Ingenuity” is defined as “an inventive, imaginative, typically American cleverness used to find practical solutions or advancements.”

This describes how I live and I think, how our developmental services system has evolved. Neither of us perfect, but continuously trying to get close. We don’t always get it right.

I’ve lived in South Burlington Vt with my husband, Steve and our son, Chris for over 35 years. We moved to South Burlington from a nearby city, so that Chris would not be put into segregated programs. But he would have the opportunity to grow and learn along with children who lived nearby and went to his school.

You see, I grew up in Rutland and as an adult, drove by the Brandon Training School hundreds of times. Little did I know how that image would brush up against my life. While I was pregnant, a friend asked my husband Steve, to coach a team of Special Olympians. I thought he was amazing for taking on such a responsibility. Ironically, during that time, our son, Chris was born with Down syndrome. Coincidentally, 2 months before his birth, District Judge, Charles A Driscow and attorneys Herbert Olson and William Reedy signed an order that would begin the deinstitutionalization of the Brandon Training School. (Remember that name, William Reedy.) But here we were, still being asked if we were taking Chris home.

You see, from the day Chris was born, we have believed it was our responsibility to make sure Chris had the same opportunities and experiences any child or adult deserves. But, from the very beginning, we were told by “experts” to be realistic or we would experience disappointment and heartache and Chris would experience failure and rejection. Undeterred, we began figuring out how to give Chris a chance to play and learn amongst his preschool peers and most importantly to fit in and be accepted. He started preschool in a special program for young children with disabilities. But immediately I realized it wasn’t going to provide Chris what we were hoping for. I thought, all of the children needed peers who could challenge them to learn how to interact and develop what I call “playground survival skills”. There was one classroom that had a mix of typical children and children with disabilities. We requested Chris be placed there, but were told “no”. We were eventually told to get legal representation to challenge their decision.

Remember the name of the lawyer in the Brandon Training School order was William Reedy, esq., a lawyer with VT Legal Aid. Four years later, represented Chris in a lawsuit to have him mainstreamed in preschool. It was a terrifying proposition. But we had the support of many other families, professionals, preschool teachers, speech pathologists, PTs, OTs, psychologists and even a school board members.

We have never denied Chris's disability, nor does he. He can tell you what it means to have Down syndrome. He was brought up to be comfortable and not ashamed of his condition. He knows it's can be harder to learn or do things others do with little effort. He is sensitive to other people who are also challenged as a result of their conditions. His greatest strength is empathy.

For the first half of Chris's life, natural supports helped his inclusion in school, relationships with peers in activities like karate, cub scouts and even the school band. But it still took support from others, to help remove barriers, so it could happen as naturally as possible.

If you haven't guessed, Chris's life gave my own direction. By the time he was 5, I had met other parents and been exposed to the most progressive ideas on how to support people with significant challenges. It began my 20 year career as an advocate for families like ours, working on public policy in education, social work, human services, day care and essential early education. I was involved in systems change in various programs, conducting quality of life assessments, for people served by our local DS agencies, using community members as trained reviewers. I was a reluctant lobbyist. I was involved in the establishment of the Self Determination project, which was the impetus for the creation of the "Self and Family Managed" option in developmental services. It is this option that has provided the supports necessary for Chris to live the last 20 years, as typical a life as possible.

The supports have been successful, in allowing Chris to live life as the rest of us often take for granted. People see him and wonder why he even needs paid supports, not realizing that the supports are there, just provided in ways that don't interfere with Chris's connection with other people, the places he goes and the activities he engages in.

The Developmental Services Self and Family Managed" option has allowed us to utilize our "Yankee Ingenuity" to make what would ordinarily happen in more structured or traditional programs where there are "trained" professionals, happen in ways that actually put Chris in the midst of community life. He goes to the local fitness center on days when the weather isn't conducive. And on a two hour hike up Mt Philo. He makes dinner and watched the Superbowl at a fraternity from which he has employed 23 "brothers" over the course of 15 years. He has ridden his tandem bike all over Chittenden County, climbed to the top of Camel's Hump.

He has a part-time job at Sierra and hopefully will return to his seasonal job in the Shelburne Farms cheese house. He is back at his post at UVM Hockey games as an events staff person where he sees many old friends. He can be seen at Barnes and Noble most days, reading wrestling or heavy metal magazines, journaling with the guidance of someone who looks like, just another customer. He has done an "Open Mike Night" with one of his support workers who graduated with a degree in literature. He has experienced being an organic gardener, making cider and beer with other young men. He is an avid and we believe, gifted photographer, having had 6 exhibits over the last couple of years. Any photos you see, without Chris in them were taken by him. But it took someone to download them onto a computer, crop them, get them printed, buy supplies to mat and frame them, find venues where he can exhibit them, including a local arts gala where amateur and professional artists display their works. He has even sold several of them.

As far as having "trained" staff to support him, Chris and we are their trainers, talking and planning almost every activity. And they bring with them life experiences and skills that allow Chris to master skills broaden his repertoire and at the same time, meet his goals. Chris has been a teacher to many of them. Since working with Chris, 3 men have become Drs, one an officer and Navy Seal, one an Outdoor Leadership and Natural Resources graduate, several musicians and several other with degrees in photography and studio arts, an editor of a newspaper, many are in finances, he's written songs with a song writer.

What comes next? His father and I are not getting younger. Chris will need support to live on his own, although he insists he needs a roommate. We will likely need the supports of a traditional agency. Hopefully he will have many more life experiences that allow him to continue leading a life that he deserves, like the rest of us do.

This is the context in which any evaluation for Chris's eligibility should include. He is more than an IQ score.