
Our Journey. . . is not the government's priority

Written by Nancy Richey

As we all know, having children is a huge responsibility and commitment. It means that for at least 12 years, you tend to just about their every want and need. Once they are teens, a whole new gamut of concerns come into play as they begin to venture into the world on their own, until they graduate and head to college or work, and begin their young adulthood. Around this time, parents typically can gradually turn their attention to other things, such as retirement and doing things they've put off for the future. Such is the picture of life we all anticipate when we venture into the world of parenting.

That is, unless you have a child with a developmental disability. Before going any further, be assured that we are neither complaining nor whining, nor are we seeking pity. Our children bring us enormous joy in both similar and different ways as typical children do, and the love we feel for and share with them sustains us when the going gets tough.

The experience of parenting a child with a developmental disability brings a very different array of challenges, worries, and struggles during those early years. None of us received a "how-to" manual for this different kind of role, so the learning curve on the front end is a steep one for parents. Understanding and embracing the specifics of the disability, navigating and advocating through the entire education system from early intervention on, finding the therapies, treatments, or specialized medical care our child needs, trying to maintain relationships with others both within and outside our families, and oh yes, nurturing a marriage and taking care of ourselves. It's a very different and often exhausting journey.

Perhaps the biggest difference from the typical journey is that there is no distinct anticipation of our child jumping out of the nest at some point and beginning their adult life with independence. We parents dream and write vision statements about a future that closely resembles the typical everyday life, but there are so many "ifs", conditions, and slippery slopes. The biggest of these is that without supports in place for our adult children, we are pretty much kidding ourselves with our dreams and vision. That vision is one of freedom, freedom to experience life to their greatest ability, not free of challenges per se, but certainly free of impenetrable walls.

I love Pennsylvania. What I have always felt set Pennsylvania apart from other states I have lived in is the genuine kindness, good-heartedness, and warmth that its people wear right up front in their interactions with others, even perfect strangers. There is a strong value system here, part of which is that hard work and determination can and will open a promising and fulfilling future. The foundation of these values, I believe, is the foundation of freedom. In his writings on William Penn, Jim Powell states: "By creating Pennsylvania, William Penn set an enormously important example for liberty. He showed that people who are courageous enough, persistent enough, and resourceful enough can live free. He affirmed the resilient optimism of free people."

Yes, optimism, resourcefulness, persistence, and courage. These words describe the 20,000+ people waiting for services and their family members in Pennsylvania. For 15 years, parents of children with developmental disabilities have been advocating tirelessly toward the goal when no one's life has to be put on hold, or worse, be held in peril, because of having to WAIT for the supports and community-based services needed in order to live that kind of free life. During those 15 years, there have indeed been good economic times as well as lean, such as we now face. Yet, even in the good times, this population has been pushed back and pushed down, evident in the fact that the waiting list for MR services has gotten longer with each passing year.

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For many families who are waiting for services, life is too complicated to allow time or energy for the basic human experiences that make life fulfilling. Actually, these people aren't waiting; they are coping, struggling to just get through each day as best they can as they care for their loved one. Those things that constitute an everyday life are beyond their horizon. Their dreams are replaced with worry, fear, hopelessness, despair and exhaustion.

Each year, the PA Waiting List Campaign, a dedicated group of parents and advocates from across the Commonwealth, digs deeper to develop our message to you, our legislators, in hopes that THIS year our message will finally strike your hearts, your commitment to ALL citizens, your compassion for those who are vulnerable, and perhaps your vision for a level playing field for everyone who dreams of a free life with open doors of possibilities.

Unfortunately, our efforts make only small steps forward at best, and at worst, we go backwards, such as proposed in Senate Bill 850.

When our young people graduate from high school, if they don't immediately step into a structured role of work, volunteering, or a day program, they regress quickly. If one parent must stay home to care for the adult child, homes may be forfeited; families may be destroyed, or worse. Supports and services are not a luxury! Those services are a lifeline without which there is no safety net.

And on the other end of the lifespan: my husband and I have three parents in their mid-80s, one living with us in our home. When I think about our situation and the three seniors in our lives, I imagine all of the Pennsylvanians in their 80s or 90s who are still caring for their own adult child with MR, in their home, little if any supports, coping as best they can simply to stay alive and get through each day. The waiting list is not just the number of people with cognitive disabilities who are waiting for services. It includes the uncounted number of moms and dads, brothers and sisters, who do whatever it takes to care for their loved one, but who are at any moment on the brink of disaster because there is no support system in place if something would happen.

I have struggled for years with what I'm afraid are the reasons we have a Waiting List. The general culture of our society places little value on people with mental retardation. It is easy to just turn away and ignore the fact that they need supports in order to live. It is a very harsh reality. Our society is a very unwelcoming place to people with cognitive disabilities. People choose to push them aside, ignore their needs, and frankly, see them as less worthy of what life has to offer. They simply don't matter when it comes right down to it. Unless that is, they happen to be your own sons, daughters, or family members. Then you step into a different world where you see the coldness and callousness that stands in the way of their everyday lives.

Disability advocates across the state will absolutely never give up until the waiting list is a thing of the past. We so desperately need champions in the legislature who will stand up for our sons, daughters, and friends and fight for their freedom and rights. Their voices spoken on behalf of our loved ones has the power to not only change lives but also save lives. Their legacy could be huge if they would firmly stand for what is right for this group of quiet citizens.

In closing, I have written vision statements for our son several times, and all of them have been realistic and do-able were there a system in place that could be counted on to fill in the supports where they'll be needed. However, there is no vision, no future for him or anyone else like him, if we don't figure out how to tackle this waiting list once and for all and keep up with the needs of people instead. Why aren't people the priority of our government?