



By Caryn Sullivan

A MOTHER'S EMPATHY

OFTEN, AUTISM DEMANDS A LEVEL OF VIGILANCE THAT'S VIRTUALLY IMPOSSIBLE TO ACHIEVE

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Driving through central Wisconsin this past week, I battled the melancholy that crawls into my heart each year at this time, around the birth date of my first-born -- my son, whose needs have driven me to near exhaustion and stretched my limits of patience; my son, who is clever and sweet and has expanded my level of compassion; my son, who should be taking his driver's license test but is not and may never do so. My son, who has autism.

I recalled how he struggled last summer with chronic health issues, a struggle that depleted me. Those issues are history now, thanks to wonderful care at the University of Minnesota. Life is so much better. In my mind's eye the scale that measured his life tipped away from the end that housed a sense of loss and despair to the end that harbored gratitude and optimism.

In a freaky coincidence, a radio newscaster interrupted my reverie to announce that local authorities had found the body of 7-year-old Benjy Heil floating in a pond less than a mile from his Wisconsin home. Benjy, who had autism and impaired communication skills, disappeared the week before from his family's basement. Scores of volunteers rallied to search for him. Not surprisingly to me, the media reported that Benjy had previously wandered away from home and one time had been discovered in the basement of a nearby house.

My melancholy quickly became despair for the parents I have never met but who had just heard the news that I feared for so many years. My first thought was, there but for the grace of God, go I. Instantly, I recalled the boy we called "Jumping Jack Flash," because he never stopped moving. Our curious wanderer who made unsupervised visits to our neighbors, rendering us breathless with panic. The boy for whom we ultimately installed a big black fence in our suburban backyard, not to surround the pool that we would have relished, but to bar him from escaping the safety of our yard. I recalled those exhausting years when we were vigilantes, anticipating and preparing for unknown dangers that were always lurking in the background. Knowing that today he would rather play video games in his bedroom than cruise the neighborhood, I concluded that my mental scale was definitely tipped in the right direction.

Thankfully, the media are now focused on the increasing numbers of children who are diagnosed with autism. But what does the diagnosis actually mean to the family whose loved one has autism? For many, autism is a lifelong condition, although it manifests itself differently over time. That means thousands of families will be dealing with autism

issues forever, whether it be with medical, behavioral, therapeutic, educational or housing concerns. The disproportionate amount of time and energy devoted to the child with autism affects the siblings, the parents and the extended family and frequently causes painful social isolation. Families often spend considerable sums to pursue every conceivable treatment option for their child. But most of all, living with autism can require extraordinary vigilance where one must always know what the child is doing and stay one step ahead of him -- a demand that is incomprehensible to most who don't live it and virtually impossible to achieve.

Learning Friday of the death of young Kaylie Dickerson, a 5-year-old girl with autism who also drowned near her home, I thought that some good can come from these tragic deaths if others who have been affected by their wrenching stories as I have will find some way to help.

For those who know a family who is living this life, help can be as basic as offering to have coffee or a beer with mom or dad or to watch their child while they shop. Those who are inclined to help financially can support the scientific research into the causes of and treatment for autism. As the autism mystery unfolds, life will improve for all who are affected by it. With that in mind, I hope that readers will dig deep into their hearts to find a way to help other families like Benjy's and Kaylie's so that their only moment's rest does not come when their child is in his or her final resting place.

And to the Heil and Dickerson families, my family extends our deepest condolences. May peace be with you.

Caryn Sullivan lives in Mendota Heights with her husband and two children. Her essay, "Dancing with Despair," is featured in "Special Gifts: Women Writers on the Heartache, the Happiness, and the Hope of Raising a Special Needs Child" (Wyatt-Mackenzie, June 2007), an anthology of work by mothers of special needs children.