



By Caryn Sullivan

The Long Road: Autism, Grief, and a Distinction that Makes a Difference

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It has been 16 years since we learned our son has autism spectrum disorder (ASD). Since that time, I have traveled a very confusing and circuitous route. At the beginning, I stubbornly resisted one professional's opinion that the ASD would endure. But recently, I sought confirmation that our 18-year-old still has ASD. That diagnosis is his passport to financial support and services, which he will need for his lifelong condition.

In 1969, Dr. Elisabeth Kubler-Ross penned the book "On Death and Dying," in which she described five stages of grief: denial and isolation; anger; bargaining; depression; and acceptance. Dictionaries define grief as "great sadness, especially as a result of death" and "keen mental suffering or distress over affliction or loss."

The Kubler-Ross stages feel awfully familiar. I recall how I could not utter the word "autism" for months; how I objected to one psychologist saying he had a disability but embraced the optimism of another who forecast a normal prognosis. Eventually, my brain thawed, and I warmed up to the heart-breaking reality that the life we had in store for our son would likely not materialize. I only did so after spending years in a shroud of sorrow, working like a contractor with a punch list to achieve the optimistic outcome and to prove that the therapist who attributed our toddler's autism to "emotional neglect" by working parents was a quack.

While I have encountered many parents who were visibly in the anger stage, I generally avoided it, until former Playboy model turned autism activist Jenny McCarthy arrived on the national scene. With no medical or scientific credentials, she claims she cured her son of autism and that others can do so, too. Despite my efforts to bargain away the diagnosis by employing every feasible and affordable therapy, it endured. I appreciate that, except in rare circumstances, those of us who were thrust upon this long and winding road are still in the land of autism – and always will be. By promising a cure, McCarthy has become an unwitting purveyor of cruel and false hope with a national platform from which to spread it. That ticks me off.

The autism spectrum contains a diverse group of people who share common traits, manifested in impaired communication and socialization. Some are highly engaged with others – but lack social judgment that would bar one without the condition from speaking to a stranger. Some, like my son, have language, but little interest in using it to converse with others, whether he knows them or not. Yet others can neither speak nor perform basic activities of daily living – grooming, dressing, toileting and more.

When rendering an autism diagnosis, Dr. Robin Rumsey, neuropsychologist at the University of Minnesota Autism Spectrum and Neurodevelopmental Disorders Clinic, never speaks of full recovery, but tries to provide some hope. Her goal is to provide families with a plan that is manageable and that addresses the child's specific areas of need, while also recognizing his strengths. Psychologist Pat Pulice, director of Autism Services at Fraser Child & Family Center, notes it is difficult for professionals to provide a balance between hope and grief and to paint a picture of reality, particularly since every child and every family is different. Parents have an idea of what they think life will be like when they have a baby. An ASD diagnosis shatters the dream and introduces a new and unexpected reality at odds with the dream.

But what of those who live with the condition? Do they go through the same grieving process, or is it the sole province of their parents? I suspect it is a complicated amalgamation of both. As Pulice notes, it can be difficult for parents to separate their children's emotions from their own. Milestones such as birthdays and graduations are painful for parents who understand their significance and are all too mindful of how others celebrate them. Both parent and child suffer when the child wants a party but has no friends to invite.

Having a verbal child, I've heard enough comments from him to suggest he, too, has gone through some of the stages of grief. Whereas in first grade, he was determined to marry a classmate, more recently, he has acknowledged he will never marry or have children because of his autism. At times, he has spoken about poor self-esteem or an awareness of how different he is from his siblings or peers. These insights add to my sadness, but also remind me that ASD is his condition, to which I am an eyewitness, not a miracle worker.

With high school coming to an end and the autism still present, I've been considering why I exhausted myself trying to fit our trapezoid boy into a round hole. Having accepted the diagnosis, I am cognizant of the danger of being an overzealous advocate or, as in McCarthy's case, a warrior mom. There is a distinction between helping someone to achieve potential and fixing someone you perceive to be broken.