

Lessons From Life: In this section, we publish insightful narratives of personal experience that conclude with meaningful applications to or implications for rehabilitation education, research, or practice. Submissions are welcome from all sectors of the disability and rehabilitation community, including educators, service providers, consumers, family members, policymakers, and fellow citizens. Follow American Psychological Association Publication Manual (5th ed.) guidelines for a concept paper, and send a diskette and three hard copies of articles for this section to Associate Editor Henry McCarthy, or contact him (hmccar@lsuhsc.edu) for feedback on an article proposal.

For Just One Day

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This essay explores the fantasy of a mother who wonders what her son would have been like if he were not severely disabled. For just one day, she confesses, she would like to know the anticipated son who disappeared from her life the day her disabled son was born, 21 years ago. The essay provides vivid examples of challenging experiences she has had with her son's autism and mental retardation, and it includes a list of recommended readings on parenting a child with a disability.

The questions college students ask when I present my family story and share our experiences raising a 21-year-old son with a severe disability always interest me. Certain ones are predictable: “What do you envision for the future of your son?” “Was the decision to have a second child a scary one?” “How do you discipline a ‘terrible two’ who outweighs you?” “What effect has Darwin had on your marriage?” But others are not. The most challenging question was posed by an undergraduate student with a disability in a human development class of 325 students.

“If you could take away Darwin’s disability and have him be normal,” she asked me, “would you?” I pondered the question for a moment. I knew that some parents would say, “No, of course not. I wouldn’t want to trade my son for anyone else because then he wouldn’t be Darwin.” But in my case, I knew that such a reply would not have been truthful. Through my mind flashed the many times I have wondered what Darwin would have been like if he did not have Down syndrome and autism. All the many fantasies I have had of Darwin waking up one morning, spontaneously talking, being fully toilet-trained, and no longer being a toddler trapped in the body of a young

adult raced through my mind. I thought of how often we have wondered what Darwin would be like if we could just somehow remove the extra chromosome in every cell of his body, magically discover a cure for autism, and rewrite his childhood to eliminate his seizure disorder. I thought of the many times Darwin has done something—whether amusing or athletic (Darwin’s gross motor skills are his greatest asset) or downright bizarre (a frequent occurrence)—causing us to wonder just how much of Darwin is *really* Darwin and how much of his personality is shaped by his disability. I thought of the future and how I worry about our ability to care for Darwin as we grow older and about who will love and provide for him if he outlives us.

For one day, *just one day*, I told the student audience, I would like to trade Darwin for the son we thought we had given birth to 21 years ago, who vanished from our lives the moment the pediatrician broke the news to us the morning after his birth that our not yet 15-hour-old son was not the baby we had anticipated.

I think all parents who give birth to children with a disability must, at one time or another, wonder what their children would be like if they were not disabled. As we

move through the phases of the cycle of loss—shock, anger, denial, grief, and eventual acceptance—at our own speed and periodically revisit one or more of these phases from time to time, we mourn the loss of the child we anticipated who suddenly vanished from our lives, the child who slipped through our hands before we had the chance to know him or her, the one who quietly disappeared into the crowd, never to be found. This mourning process, which I imagine to be similar to experiencing a miscarriage or the premature death of a child, is a necessary step before we can move on and begin to accept our disabled children into our lives.

And some of us, perhaps more than others, at times wonder about the son or daughter we were never given the opportunity to know. We occasionally indulge in fantasizing what our child might have been like. At times we find ourselves scanning unfamiliar faces in crowds, unconsciously searching for that missing child in our lives. There's a subconscious feeling always lingering that our missing child must be out there somewhere. And there is a profound feeling of loss that never fades away, despite the intense love we feel for our disabled sons and daughters.

For just one day, I would like to be able to peel off the layers of disability that for the most part define Darwin now and come to know the son of my imagination lurking like the frog prince beneath all those layers. Here are a few of the things I wonder about as I imagine meeting for the first time the son who only exists in my maternal imagination.

What would it be like to have a real conversation with our fantasy son? Darwin is nonverbal and communicates with us only through gestures and actions that require creative interpretation and educated guesswork. His receptive language is limited to only a few short phrases that need to be repeated again and again for him to retain them. In our 21 years together, I have never had the opportunity to engage in a mother-son conversation with Darwin. My fantasy son and I would have a lot of catching up to do!

What would our fantasy son look like? Our two sons are an interesting contrast of long and lean versus short and chunky. While our "normal" son of 18 years resembles his parents in many ways, our disabled son looks like the cousin of every other child with Down syndrome in the world. If the extra chromosome in each cell in Darwin's body could be removed, would we still be able to recognize him?

What would our fantasy son be like? Would our fantasy son have inherited his father's sarcastic wit or his mother's sensitivity? Would he define himself more by being (like his father) or by doing (like his mother) or by a combination of the two? How would he take to the role of big brother after being the little brother, cognitively, all these years? And how would this role reversal impact his younger,

"big" brother? Would our fantasy son tend to be introverted and cautious, like his parents and brother, or would he turn out to be an extroverted risk-taker, rappelling steep cliffs or driving for NASCAR? Would he be a "space cadet" at school, like his brother, or a National Merit Scholar? Would he have a voracious appetite for reading, like his mother and father, or a fascination with eastern religions, like his brother? Would he listen to REM or DMX? Identify with "Zits"? Be a Yankees or Cardinals fan? Pierce his nose or get a tattoo?

Would our fantasy son be a "real man"? Would he eat quiche, like Darwin? And unlike Darwin, would he have real friends and a social life?

How would our fantasy son view the world? At age 21, our fantasy son would at least have some beginnings of political awareness. Would he have leftist leanings, like his parents, or rebel against their liberalism, pacifism, and environmentalism and join the Marines, drive an SUV, or agree with Bill O'Reilly? Would he tend to be cynical, like his dad, or more idealistic, like his mother? Would he care about disability rights?

I think it is safe to assume that, unlike Darwin, our fantasy son would be toilet trained, sleep through the night, be able to carry on a conversation, dress independently, eat without making a total mess, brush his own teeth, blow his nose, shave himself, be literate, and not require constant supervision. Unlike our disabled son, he would probably *not* drool almost constantly, spit randomly, snatch boxes of cookies out of the grocery cart of unsuspecting shoppers, put his undies on over his pants, listen to the same 10 CDs over and over, try to escape out the front door and visit the neighbors in his birthday suit, toss library books in the bathtub, or roll down the car window and fling his shoes and socks out in a matter of seconds, just to create mischief and keep his parents on their toes.

At age 21, our fantasy son would be on the verge of adulthood and undoubtedly would be breaking away from us, just as his younger brother is now, demonstrating his need for independence. He might be going to college, serving in the Peace Corps in Rwanda, flipping burgers at the local McDonald's, or playing tight end for the Green Bay Packers instead of taking his favorite Bumble Ball toy and Dire Straits CDs to a program for disabled adults day after day, oblivious to what is happening beyond his narrow world.

For more than 7,700 days, I have wondered about the son I thought I was giving birth to 21 years ago. Although I got over mourning his disappearance long ago, when I began to embrace my new identity as "Darwin's mom," I still wonder about that other son every so often. I can't seem to let go of that occasional fantasy that he is out there somewhere among the 6.3 billion people roaming the earth.

And for *just one day*, I would really like to know him.

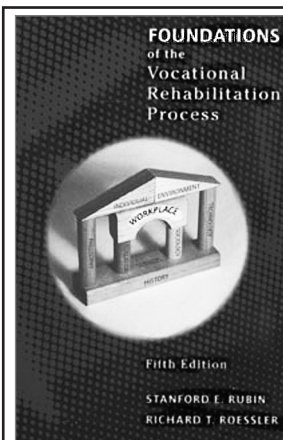
ABOUT THE AUTHOR

Susanne Carter, MS, is the mother of two sons, one of whom is severely disabled with Down syndrome and autism and is now 21 years old. She works as a grant writer in the College of Education at the University of Missouri–Columbia and serves as a senior consultant for the Consortium for Alternative Dispute Resolution in Special Education in Eugene, Oregon. Ms. Carter has published several essays on the realities of living with a severely disabled child and regularly shares her family story with college classes. Address: Susanne Carter, 911 Sunset Lane, Columbia, MO 65203; e-mail: cartere@missouri.edu

SUGGESTED READINGS

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