

I JUST WANT TO BE HIS SISTER

Introduction
By
Lynne Tamor

My daughter wrote this essay as part of the package of materials she submitted with her college applications. Once I finished cringing at her opening, which recounts an episode that I remember dimly and quite differently, I found what she had to say almost stunning. As a parent, I had been hung up on the issues surrounding her probably future role as guardian and protector, as well as companion and friend, of her younger brother. I had not thought all that much about the nature of the relationship between the two of them, and especially not about how that relationship would be maintained and transformed after Rachel left home. Clearly, Rachel had thought a great deal about this.

By way of background, readers may find it useful to know that Rachel's brother, Isaac, was born just before her fifth birthday. She was then, as she is now, intensely intellectual and caught up in the world of words and ideas. Her favorite activity back then was having "an argue". Her brother was born with a chromosome abnormality that is responsible for, among other things, many irregularities in his brain. At the time the essay was written, he was 12 years old. Very sociable, and thoroughly enjoying his life as a sixth grader fully included at his local middle school, he was nonverbal and generally considered to have severe or profound cognitive disabilities. In the words of the social service system, he requires assistance with all of the activities of daily living – a very great deal of help, in fact. He has vision difficulties, seizures, and many motor and sensory issues. He is also extremely curious, and shares his sister's taste for comedy and for people over possessions. Readers who visit the Whole Schooling website can see film clips of Isaac when he was in the fourth grade.

The Article

By
Rachel Sugar

"You don't love him," she growls, "You wouldn't care even if he died." Her eyes spit on me—"would you?" My mother is crying. Burrowing into my down comforter, I close my eyes, waiting for a wave of self-righteousness to wash over me: how dare she accuse me of not loving my own brother? Instead, my thoughts come up twisted and blank. I don't know if I love him, I don't even know what that would mean. Of course I would care if he died. Of course I would care. But beyond the requisite sorrow, I don't know what I would feel. I am paralyzed by a fear of nothingness.

I imagine hospitals, empty rooms, hushed sobs...and then I shut down, unwilling to see more. What if I were solid and not a veiled shell of some former self, too resilient to be real? I can't play out my mother's accusations in my head. What if they are true?

I am most comfortable relating to people intellectually. I've formed my closest friendships making sense of *The Crying of Lot 49* and passing judgment on Eliot, Roth, and Austen in coffee shops. In the frothing argument, debate, and sparring, I can revel in love, feeling secure in friendship, finding more happiness and warmth in arts and ideas than in a world of already-named objects. I want to do the naming, deploying language for its clarifying possibilities. I am a writer: I name things, affix words and structure to abstract formlessness. I struggle to capture the elusive and the fleeting, cementing it, preserving it, turning emotional fragments into linguistic phenomena.

My brother does not have language, or if he does, I cannot understand it. He cannot talk, and we don't know how or to what degree he processes language. Isaac has control over the signs for "yes," "no," and "more." Sometimes he seems to understand everything that goes on around him, the jokes we tell at the dinner table, our plans for tomorrow. Other times he seems oblivious to his surroundings, to my mother's requests, to his television blaring in the background, to my voice.

My mother and I have the same recurring dream: he has understood everything all this time; he has just been fooling us all. He seems so aware that I cannot quite put the thought away. Just beyond the edge of reason, it seems as though it could be true.

Meanwhile, I forge relationships with words and I use words to forge relationships. I gauge my love with language. I express my love with language. I understand people by the juxtaposition between what they say and what they do. I know where I stand with someone by what we say and how we say it. Language links to abstract concepts beyond itself. Love.

I know that I love Isaac fiercely. But our relationship is – and must be – beyond words. How, then, do I know what I feel? Loving him is an essential part of who I am, but with each summer I spend away from home, with each step I take toward leaving for good, I panic, fearing that my love has atrophied, that somehow I've lost it out of convenience, that whatever I feel, it isn't going to be enough. In the future, how will I call up my love for him without the reassurance of shared memories? If we could fight, ripping each other apart with words, I would feel an intensity passionate enough to elicit fire. But we are not, and never will be, confidantes. I once imagined us rolling our eyes at my father's corny jokes, at my mother's obsession with irrelevant details. But without words, smirks, and pet peeves to share, I don't know how to sustain a connection with my brother.

I do not want to be his mother or his caregiver, compromising his independent identity while changing his diapers, dressing him, feeding him. Neither do I want him for my puppy, part prized doll, part invisible man. I want to be his sister.