



JACK'S LIFE: REFLECTIONS ON MOTHERHOOD IN TROUBLING TIMES

One way to explain what an anthropologist does is to say that she tries to describe what it is like to be someone else. All that time spent living with a group of people unlike oneself is meant to illicit stories, anecdotes and descriptions that illuminate, at least in a partial sense, the experience of some cultural "other." In surrounding oneself with "difference," the thinking goes, one's own culture becomes more visible. I was familiar with this process of self-discovery as an anthropologist conducting research in South America, but despite such cross-cultural forays, I was entirely unprepared for the cultural immersion I experienced, quite abruptly, with the birth of my son Jack in 1998. Within days of meeting my son, I found out what it was like to be someone else: not just a mother, a stunning enough transformation in and of itself, but a mother of a child with disabilities.

The immersion began with a difficult pregnancy. Suddenly I was a "patient," thrust into a strange and unfamiliar culture of medicine, doctors and endless tests. I learned quickly that the language of medicine is expressed through countless acronyms; I came to understand the difference between an AFP and an NST, and could talk with the doctors about PIH, PET, and HELP. It gave us a sense of control to be able to "converse with the natives" in their language, but the testing and monitoring, and waiting, was still a powerless and stressful time. Immersed in the foreign culture of the hospital, the strangeness only exacerbated the sensation that I had lost control of my body and the health of my baby.

As it turns out, the rocky pregnancy would only be our initiation into a world I hardly knew existed before. A week after he was born, our son was diagnosed with a rare genetic condition that typically causes growth and mental retardation as well as a variety of other problems. So now my son was the patient, and we were by turns his desperate parents and his determined advocates. Teams of specialists descended on the small isolette (a kind of NICU crib) that held our five-pound baby. The doctors talked of scientific papers they could write; they took pictures. The rarity of his disorder was cause for considerable interest and activity. Overnight his medical file seemed to mushroom.

The diagnosis was our first taste of what it was like to have a child who, for many, represented a disorder, a medical diagnosis. The contradictions between the baby we knew, responsive and sweet and beautiful, and the baby the doctors described for us as a series of "maybes" (maybe he will grow, maybe he will develop, maybe he will need this specialist or that treatment...) were painful and confusing and terrifying. Michael Bérubé writes of a similar experience with the birth of his son, who has Down Syndrome. He describes how he got to know his child as a series of test results and medical procedures before he got to hold him and know him as a baby. "When Jamie finally came home," Bérubé explains, "he came home as a thoroughly medicalized child. Not merely 'medicated,' but medicalized: to talk about him was also to talk about his procedures and prospects in medical terms, and he already had a hefty medical chart to prove it."

So one of the first questions we faced was who was this baby? Well-meaning people gave advice: "Treat him normal," said the neonatologist; "All he needs is your love," said others. We clearly favored the less clinical of his dual identities, but much as we would have loved to ignore and deny the clinical, how could we? We were his loving parents, who were proud of him and wanted others to see him first and foremost as a child, a baby, a whole person, and yet we were also his responsible guardians, his advocates, in the 1990s language of child welfare. And so we read voraciously, but reluctantly, all the literature we could find on Jack's disorder. What had happened to other children? Who was the top specialist in the world? What tests did Jack need? It was impossible to tell from those articles what we really wanted to know: what were those children like? Did they play outside with their friends? Did they eat peanut butter and jelly sandwiches? Were they happy? We didn't really care what metabolic pathways were involved in the disorder; we wanted to know what all our lives were going to look like. We brought stacks of this literature to the specialists. "We haven't seen that one, can we copy it?" They would say. We felt like partners, like advocates. But the truth was we didn't understand much of what we read and felt

overwhelmed by the responsibility of making decisions for our fragile baby.

Another anthropologist, Gail Landsman, has written about her own experiences raising a child with disabilities. She explains that while new legislation in the 1980s and 1990s has been very important in empowering the disabled and their families, many families do not feel that they have the knowledge to make such “choices” on short notice. “With no experience and few role models from their own lives, these mothers take on the tasks of negotiating individualized service plans and integrating their children with disabilities into mainstream society,” Landsman writes. Ironically, the laws meant to facilitate the inclusion of disabled children in society may also contribute to a sense of isolation for the parents, she argues.

When this rhetoric of choice is combined with “professional distance,” or even “professional aversion” as one author described, the parents feel even more alone in making difficult decisions. For the most part, we were grateful for the excellent and sensitive care we received from various specialists, social workers and nurses. Many of them remembered our child’s name and seemed to recognize how difficult our situation was. One resident who helped diagnose Jack spent a weekend reading everything she could find about the disorder so that she could answer our questions.

Nonetheless, we ultimately felt very alone in making decisions for our son about what tests would be done and what services he should receive. There was no treatment for his disorder, but there were still many decisions to make about his care. The pediatrician, the one from whom we perhaps expected the most in terms of empathy and guidance, seemed the least willing or able to give it. She seemed uncomfortable and disengaged in our presence, referring constantly to Jack’s file as if she hardly remembered the particulars of his case. She called us at home only once, and that was to deliver test results that turned out to be incorrect. She seemed not to care, which confused and frustrated us, but now I see how it must have been for her, faced with demanding parents and a child who could not be fixed. Maybe she cared too much.

The other irony with the emphasis on “choice” in Early Intervention Programs and medical care for the disabled is that the term suggests that we control the things that really matter in our lives. One of the first lessons a parent of a child with disabilities learns, however, is that in fact we have very little control over almost anything of consequence. A sense of “lost

innocence” is especially profound for parents who believed that doing everything right would guarantee a healthy child.

Along with the anger that parents feel is often a sense of failure, which can be reinforced by the responses of others. Advances in prenatal diagnosis and neonatal medicine have led to the widespread belief that most disabilities, or in this case genetic anomalies, can and should be prevented. The uninitiated, who don’t understand that things happen beyond our control, wanted, and sometimes demanded, an explanation. Many asked, “Didn’t you have an amnio?” As if that alone would have guaranteed a healthy outcome. Even medical staff, who surely understood that amniocentesis is capable neither of diagnosing all disorders nor of preventing them, asked this question. I always answered defensively, as if I should explain how I had let this happen. Eventually I just stopped answering. We worried, as many parents must, about the value of our son’s life. If a critical gene is missing or defective is the person “whole?” What purpose might their life serve? Can that purpose justify the suffering that they and their families endure? I sensed that others were asking the same sorts of questions. Was this birth a cause for celebration or despair? For us it brought both in equal measure.

After a while, people seemed to absorb the shock of it. Little blue outfits and fuzzy toys began to arrive. We took Jack to the park and to Starbucks and on rides in the car. We “treated him normal,” following doctor’s orders. He kept us up all night; diaper changes were calamitous and hilarious occasions. He wasn’t so different after all, we said. We pressed on. We talked a lot about wanting normalcy in our lives again. Eventually, I stopped feeling dishonest when I accepted the compliments of strangers who cooed at our beautiful baby, unaware of our family drama. We were parents; we held our heads high.

I made plans to go back to work. That had always been the plan. I could do some of my work at home and I thought the time at work would help restore some normalcy to my life. My husband was working at home that year, so we only needed part-time childcare. Finding someone who was both qualified and willing to help care for our son turned out to be a challenge, however, as we found out firsthand about the shortage of childcare for the children with disabilities. Eventually, I found a private organization that helps match specially-qualified childcare providers with parents. Still, I had to face my feelings about leaving my baby behind while I went to work. This is a familiar enough scenario—working mother returns to work with feelings of regret, guilt, and a determination to continue her career. In my

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case the guilt, and the sense that my baby needed me, was even stronger. Yet we felt that as a matter of survival we had to continue with the original plan or allow our lives to be totally consumed by this disorder.

I distinctly remember thinking, as I finished my first class on my first day back at work, that I had made the right choice. It felt good to be a professional for an hour, to get my mind off of the troubles at home. Moments later, however, I was told that my son had died in his sleep. I know my absence did not cause Jack's death, but I imagine I will always question the wisdom of trying to do it all. Jack only lived for three months, so my experience with raising a child with a disability is limited in some respects. But I have a keen sense of the added burden families of children with disabilities face when balancing the competing demands of work and home.

Looking back on it now, it seems strange to me that we ever questioned the value of his life. So many lives have been changed by his brief presence that I honestly cannot remember what the world was like before Jack. We knew the value of his life even before he died and we wanted him to live, even as we grieved the loss of the baby we had hoped for and expected. As an eleven year-old friend of the family said, "He was very quiet, but he was very loud, you know?" And that's just how he was.

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