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## The Ordinary Experience of Choosing to Parent Extraordinary Children

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Down syndrome diagnosis will never define your child or your family.

**Postscript:** Now in 7<sup>th</sup> grade, our son continues to flourish. He is successfully taking gym, choir, Spanish, and social studies alongside typically developing students. Additionally, he competes in taekwondo tournaments and is currently ranked #1 in the state for weapons.



## The Ordinary Experience of Choosing to Parent Extraordinary Children

Ryan H. Nelson & Kendra Lystad

**B**efore we knew anything else about our daughter, F, we knew she would have Down syndrome. We knew not because of prenatal testing or parental intuition, but because we had just registered as prospective parents with the National Down Syndrome Adoption Network. So, when we got word, a few short months later, that we had matched with an infant two states away, her 47 chromosomes came as no surprise.

In hearing the stories of parents who have biological children with Down syndrome, it has become clear that central to the experience of many is a process of reconciliation: reconciling the future they had imagined for their child with the reality of a rather different one. In broad strokes, Down syndrome changes nothing. Parents still want their children to be joyful and kind, to fulfill their potential, or to do whatever it is that makes for a good human life. But the particulars require adjusting. The milestones and achievements parents tend to envision for their children may need to shift, or be done away with altogether. And though most eventually reach a point where the actual overtakes the hypothetical, we often hear the process described as one of grief—grief for the loss of a child who never existed but who seems real nevertheless.

Our experience as adoptive parents lacks this particular emotional core. Because we had never imagined an alternate future for F, we were never forced to confront the disorientation of the

unexpected. The Down syndrome community has been nothing but warm and welcoming to us. Yet we can't help but wonder whether some within it regard our parenthood as different, in an essential sense, from their own. Perhaps we ended up parents to a child with Down syndrome in the same way Rosie Ruiz finished the Boston Marathon, bypassing its foundational struggle.

What does it mean to *choose* to parent a child with Down syndrome? Many, of course, choose in one way or another. There are choices to be made, at least in some jurisdictions, by those who receive a diagnosis during pregnancy. And there are choices to be made even by those who don't receive a diagnosis until later, as was the case for F's birth parents. Our choice, though, was defined more by agency than circumstance, pursued rather than confronted. We never found ourselves having solemn discussions with physicians and genetic counselors or paging through a stack of adoption profile books filled with smiling people hoping desperately to be chosen. Compared to the decisions so many others encounter, ours was easy.

This is not to say that the process has been unemotional. F was one month old when she was placed with us. Quite unusually, we met her for the first time at her birth parents' home, a single wide in the country surrounded by orchards and hop fields. They were clearly loving and capable people, but, for reasons beyond their control, felt unprepared to parent a child with complex needs. Seeing their anguished faces as we strapped F into the car seat we had unboxed just the day before was among the most affecting experiences of our lives.

With every challenge that has come along with parenting a child with Down syndrome—attempting to sleep in the ICU with an infant who just had open heart surgery, arguing for inclusion with the principal of a school whose motto is "All Are Welcome," futzing to remove ear wax from tiny hearing aid tubes—we remind ourselves that we opted in to this. And we did so not because of some moral imperative or divine calling ("God's plan" is referenced in nearly every published account of Down syndrome adoption), but because we *wanted* to. We wanted to do a thing, and we did it.

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Five years after coming home with F, we decided we were ready to adopt again. Another mountain of paperwork. Another home study. We initially registered with a generic adoption agency but eventually found our way back to the National Down Syndrome Adoption Network. Again, things moved quickly once we were active on the registry. Before we knew it, we were meeting another pair of birth parents, this time in the gleaming metropolitan high-rise where their adoption agency has an office. The birth mother entered carrying a sleeping five-week-old girl. Half an hour later, we were hailing a cab with our second daughter, M, still sleeping, in the same car seat her sister had used.

Our family and friends have expressed and demonstrated unfailing support of our choices. There have been no sly comments about disability, no third-hand adoption horror stories, no handwringing about our future or the kids'. But, naturally, we encounter people who are curious about our motivations. Did you struggle with infertility? No. Don't you want to have "kids of your own"? No (if you must put it that way). Do you have family members with Down syndrome? No.

While motivations are never perfectly transparent, we are confident about a couple of things. For one, we reject the notion that biological relatedness is itself valuable, which is something of a hot topic at a time of rising pronatalist (and pseudo-eugenicist) sentiment. For another, we consider ourselves to be well-positioned to parent children with Down syndrome. In addition to having the privilege of financial security and a strong social support system, our personal and professional experience have increased our comfort and familiarity with disability and what it entails. We would never claim to have been fully prepared for what was to come, or that we now know all there is to know, but we were confident in our choices and remain so.

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Discussions of Down syndrome often struggle to avoid the twin traps of pity and exaltation. Whereas some see people with Down syndrome as tragic figures who are "blessed to have loving parents" (as a well-intentioned stranger might say to us in the grocery store), others see them as a monolith of

innocence and light ("Oh, I just *love* Down's kids!"). But a Manichean discourse about Down syndrome risks obscuring what we have come to regard as the defining feature of parenting our children: its ordinariness. It would be unfair to deny the distinct challenges associated with parenting children with Down syndrome (not to mention living with Down syndrome). So, too, for denying its joys.

Our kids, like all kids, comprise idiosyncrasies, complexities, and contradictions. And we as parents do our imperfect best to see them fully and to provide them an environment in which they can flourish. On a given Tuesday, this translates to us doing the kinds of things any other family with two small children might do—from the Sisyphean routine of sweeping up far-flung bits of cereal after breakfast to the relief of crowding into a rocking chair after dinner to read the same book we've read a hundred times before. Ordinary.

F is eight now. Her heart is fixed; she's attending a school that is happy to have her; she has hobbies and friends. M, also now with a healthy heart, is two and loves to entertain us with her antics. We realize that, as they get older, the differences between them and their typically developing peers will become more pronounced. In some ways, their lives will become more extraordinary, and perhaps so will ours. But, for now, parenting children with Down syndrome just feels a lot like parenting.



## On Happiness and Heart Defects

Anne Penniston Grunsted

**M**y wife and I have one child, a seventeen-year-old son with Down syndrome. Bobby is a limited communicator, meaning he struggles to tell us his thoughts and feelings. However, he is also affectionate, funny, and well-liked by those who take the time to bridge that communication gap. He is mindful, generally focusing on the present moment rather than worrying about the past or future. He is accepting of others. And,