

Parenting a child with health challenges

A story of vulnerability and hope

Kimberly Penner

Through newborn genetic screening, my partner and I learned that our child has a serious genetic disease. After working through the initial grief and shock of the diagnosis—some of which I analyze below—I remember thinking to myself, *I am going to be a much better parent because of this*. Many of the concerns I had previously—for example, about sleep deprivation and balancing life as a mother and an academic—slipped away. The vulnerability I experienced because of the reminder of human fragility I received replaced these worries with gratitude and joy for my child’s existence and a commitment to love him and others deeply and fiercely. I continue to feel this way, though it is not always easy. Vulnerability and gratitude do not remove fear and suffering. In what follows, I first reflect on notions of “normalcy” around ability and disability that I became aware of in my grief and that ought to be dismantled. Then I offer a theological understanding of hope that acknowledges God’s presence with us in our suffering and vulnerability.

The cult of normalcy

After the initial shock of our newborn’s diagnosis, I experienced a strong desire to distance myself from the baby. I have analyzed this reaction since then because I found it so surprising. I think it reveals a lot about the expectations I had—and that our society has—about criteria for an ideal baby. Certainly, part of my reaction was a biological response to protect myself from the pain of potentially losing my child at some point. However, it was also an indicator of a subconscious preference that I had for a “perfect” baby and “perfect” birth experience, including “perfect” health and ability. I felt “abnormal” and immediately “other.”

As long as it is healthy is a phrase we hear and repeat regularly regarding the birth of a child. I remember my midwife bemoaning this fact. She felt that the real joy and hope around pregnancy and childbirth was not

dependent on or encapsulated best by “perfect health” but rather simply the existence of, for however long, a life that was wanted; the relationship, not the state of health, is a criterion for worth. I only learned this from her after our child’s diagnosis. Or as Kate, mother of a child with cerebral palsy, writes:

I signed up to be a Mom. Just as I wouldn’t say, “As long as it’s smart” or “As long as it’s good looking” or “As long as it’s straight” . . . I wouldn’t say, “As long as it’s healthy.” . . . When we sign up to have children, we aren’t guaranteed anything. They could be born with a disability or develop one years later. They could be born with a defect or develop defects of character as adults. The important thing is that they are ours.”¹

I agree and would add that our children are important not only because they are ours but also because they are God’s.

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is promoted by societal attitudes about the value of bodies. It “takes the exchange values associated with bodily appearance and function—that is, how useful, productive, or valuable certain bodies are in particular social exchanges—and it routinizes them through systems of power and associated rituals.”² For example, we tend to value bodies that are self-sufficient and contribute to the economy. Beautiful bodies are also highly valued, and value judgements are made of bodies outside of this norm—

those who are “overweight” are considered immoral, gluttonous, lacking in self-control, and unproductive, for example. As Reynold’s explains, in the cult of normalcy, what was once considered only an ideal (however problematic) is now desired as the norm, and “the normal functions as

1 Kate Leong, “As Long as He’s Healthy,” Chasing Rainbows (blog), September 4, 2012, www.kateleong.com/2012/09/as-long-as-hes-healthy.html.

2 Thomas E. Reynolds, “Disability and the Cult of Normalcy,” *Christian Reflection: A Series in Faith and Ethics* (2012): 28, www.baylor.edu/content/services/document.php/188186.pdf.

normative, a way of controlling bodies and judging differences deviant.”³ In this way, “the perfectly sculpted and athletic body [is, for example,] presented as commonplace, even though it actually represents only a slim margin of thin people.”⁴ In the cult of normalcy, the body is “seen as an objective marker of the good,” and for this reason especially, it requires theological analysis. What makes embodied people good and valuable in God’s eyes?

My reactions to my child’s diagnosis—namely, my desire to distance myself from him, which included a desire to start over with a different pregnancy, reflect, at least in part, the influence of the cult of normalcy on my views of pregnancy and parenthood. Subconsciously, I valued health and ability as normal and desirable. And while a diagnosis of this kind most definitely warrants fear and sadness, as people of faith our hope and joy are not dependent on good health or the good health of our newborn children.

Vulnerable communion

Our hope and joy regarding the gift of children and parenting come from God’s willingness to be in what Reynolds refers to as “vulnerable communion” with us through each other and with creation—that is, relationships of mutual giving and receiving out of the vulnerability that each of us experience as created beings.⁵ What we ought to celebrate about parenting is the gift of the relationship with our child. This relationship exists regardless of the health of the baby—at birth and throughout life. Yes, health is important, but it should not be a criterion for determining the worth of our children or birth experiences. As another mother of a child with health issues writes, “‘unhealthy’ is still a place of love and joy and life. It’s a place of resilience and strength you didn’t know you had, and community that will envelope and hold you up. It’s a place that teaches you and humbles you in the same breath as it strips you bare and builds you up. And when all is said and done, it’s a place where your child is, and there’s no other place you want to be.”⁶

3 Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids: Brazos, 2008), 60.

4 Reynolds, *Vulnerable Communion*, 61.

5 Reynolds, *Vulnerable Communion*, 245.

6 Tessa Prebble, “Living on the other side of ‘As long as it’s healthy,’” *The Spinoff*, January 25, 2017, <https://thespinoff.co.nz/parenting/25-01-2017/living-on-the-other-side-of-as-long-as-its-healthy/>.

While I did not choose to become so aware of my vulnerability as a parent and a human in this way, it has given me greater insight into the love of God, the value of relationships, and a Christian understanding of hope. While hope “arises only with a felt lack or deprivation, and in terms of an acknowledgment of vulnerability,” it does not passively yield to suffering.⁷ Rather, it opens to a vision of what is possible given the love of God. To reiterate, while suffering does not disappear with hope, hope brings with it the reassurance that God, like us, is vulnerable and is with us in our vulnerability and suffering. The more vulnerable we are willing to be, the more open we are to seeing God through others. The relationship, not the suffering and pain (and not the state of good health or ability), leads to greater joy and wellbeing. As Reynold’s explains, “God is in solidarity with humanity at its most fundamental level, in weakness and brokenness. This is not to romanticize weakness. Here in Christ, God reveals the divine nature as available to creation not only by undergoing or suffering with human vulnerability, but also by raising it up into God’s own being.”⁸ And the hope that Christ’s resurrection from the dead offers is that no matter what suffering or loss we might face, God’s redemptive purposes cannot be stopped; tragedy will not have the last word.

My experience with vulnerability as the parent of a child with health concerns is ongoing. During this pandemic, I have greatly appreciated the privilege of being able to stay at home with both of my children in the safety of our social “bubble.” In this bubble I can guarantee their protection from most of life’s concerns, not least of which is life with a genetic disease. I worry about how hard it will be to let them out of this bubble again. Yet, I also know the value in letting go of my fears in faith and hope. I celebrate the fact that there is room for all these feelings in an understanding of Christian hope in Christ. I am grateful that my experience with vulnerability has revealed this to me.

About the author

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7 Reynolds, *Vulnerable Communion*, 142.

8 Reynolds, *Vulnerable Communion*, 177.