“Do you think you know Megan?”

Megan is a thirty-four-year-old woman with cerebral palsy and a significant cognitive impairment who lives in a group home. She is barely verbal, difficult to understand, and, oddly, when she does speak, says everything at least twice in direct succession. She works a few hours a day at McDonalds during the week cleaning up the dining area. On weekends, she goes to church with us. She can’t read, so she makes unusual noises during the songs and the recitation of the Apostles’ Creed. Her friend, Seth, who has Down syndrome, now comes with her, and they always sit near each other. Once when we were out of town, Megan went to church by herself. Her phone made noise during the service, and she was unable to turn it off. She left.

Do you think you know Megan?

Let me try again.

Megan is a resident at Friendship House, a residence on the campus of Western Theological Seminary where seminary students share housing with young adults with intellectual disabilities. She delights in her housemates, and they are her best friends. She sometimes exercises, prepares meals, or creates artwork with the seminary students. On World Down Syndrome Day this past year (always March 21 to symbolize the value of the extra, or third copy of, the twenty-first chromosome in people with Down syndrome), four of the Friendship House Friend residents were looking forward to being acknowledged and celebrated. Megan does not have Downs, but her friends wanted to make sure she was included. When my wife pointed out that Megan didn’t have Down syndrome, they insisted, “Megan has Downs.” Megan nodded her head vigorously and repeated in affirmation, “Yes, I do . . . yes, I do.” Why should she be excluded yet again, this time because she has the “wrong” disability?

She has difficulty communicating verbally and knows it, so in an effort to make sure you can understand what she is saying, she tends to say things at least twice. Every day during the work week, Megan takes public transportation to her job. Once a week she rides horses at a therapeutic riding center. On her way to work, she often texts her friends the emoji of a hamburger, and when it is time to ride, she texts an emoji of a horse. On the weekends, she joins my family at church (and texts us an emoji of a church to let us know she is there and waiting for us), and she is an important part of our community of witness. Though she can’t read, she participates in all aspects of the worship service and offers habituated responses to the music and the recitation of the Apostles’ Creed. Megan has a contagious enthusiasm about church and emits a profoundly joyful and largely nonverbal witness to being included in the body of Christ. When she invited her friend Seth to attend church with her, of course he came. Everyone wants to be loved and included; everyone is looking for a place to belong.
Soon after joining us at church, Seth was baptized.

One Sunday when we were out of town, Megan attended church by herself. She sat in the balcony where we often sit together. No one sat close to her. During the songs, no one found the correct pages in the hymnal for her. At some point during the service, her phone began to buzz, and she was unable to turn it off. People around her “shushed” her and looked at her in a way that she interpreted as harsh and angry. No one helped her. She began to cry. No one comforted her. She quickly left church, ran home, and cried. In the three years we have known her, Megan and her friends from Friendship House have the chance to gather and share highs and lows from the week with my wife and each other. In that time she has had only two lows. One was when my son stopped by McDonalds when she was working; he didn’t see her, so he did not greet her. The other low was when her congregation failed her: they didn’t make room for her, didn’t value her contribution to the church, and didn’t seem to want her witness.

It should be obvious that Megan is not suffering because of her cerebral palsy or limited intellectual development. In fact, she is generally one of the most joyful people I know. She does, however, suffer when she feels unwelcomed, excluded, or like she doesn’t belong. Don’t we all? We must complexify the common-sense belief that all people with disabilities suffer as a consequence of their impairments. Unfortunately, disability and suffering are frequently paired in the relatively few seminary courses that engage the lived experience of disability and in books and curricula that address disability from a faith perspective.

I don’t want to over-interpret Megan’s life and appropriate her experiences in an instrumental way to make my points. Much of my retelling of her story is my attempt to allow her to “speak for herself” when words are difficult for her and to allow her to offer a word of challenge to the church. I want to acknowledge that Megan’s involvement at church, my familiarity with her, and my awakening to her indispensability as a part of a witnessing community are among the many experiences that led me into the type of theological inquiry found in this book.

— Taken from the introduction