

Religious Inclusion: One Pilgrim's Learnings

The birth of our second son, Justin, 10 years ago, brought a new and unexpected challenge to our lives. Justin was born with myelomeningocele, also known as Spina Bifida. Spina Bifida is a condition that occurs in the first 4 weeks of pregnancy. The baby's neural tube, which develops into the brain, spinal cord, and vertebral column, does not form properly. This results in varying degrees of permanent damage to the spinal cord and the nervous system, including the brain.

For Justin, this means he has limited sensation and use of his legs, bowel and bladder incontinence, and a shunt in his ventricles to drain the extra fluid in his brain. He is keeping up with his peers in school, and is an award-winning soap-box derby car racer.

As with all new parents of children with a disability, Justin's birth meant adjusting to a new, unexpected path. It has challenged our views of God and our church community. I like to think it has enlarged this God we worship. In this article I would like to share with you lessons I have learned related to God and the church congregation.

People will have different answers to the question of why God allows or causes people to have disabilities. Allow a person the time to find his or her answers. Offer your "answer" only when you are asked.

The first night after Justin was born I was forced into rethinking my understanding of God. A woman from the housekeeping department came into my room late in the evening and happened to catch me crying. She asked if I believed in a miracle-working God. What could I answer? It was a Catch-22. I couldn't say "no." Yet the implication of "yes" was, if I simply *believed*, then my child would be healed. I prayed, my family prayed, our church prayed, and our friends prayed. Justin still has Spina Bifida. I am learning some satisfactory answers, and I am also learning to live with unanswered questions. It has taken time.

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There is a difference between "healing" and "cure." Do not let "cure" be the stumbling block between you and your child or between you and God.

God is working a miracle in me. As I have interacted with adults who have disabilities over the years, I have come to realize there is a difference between *healing* and *cure*. Recently, I was in a meeting with a pastor who had cerebral palsy. He said when he arrives at heaven he believes he will still have cerebral palsy. The miracle is that it (having cerebral palsy) won't matter." Justin needs healing from the very sins that all of us need healing from. I continue to pray for this healing just as I do for my older son who society would say is "well."

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The church community can and should be a source of strength and support to families and individuals affected by a disability. Look to the church as a resource.

We had moved back to our home area shortly before Justin was born and had not settled on a church to attend. When the church we had been visiting learned about Justin's birth, they simply wrapped their arms around us like members. We received pastoral visits, cards, financial gifts, and after we were out of the hospital, meals brought to our home. We eventually became official members of this congregation and the support has continued in a variety of ways. The most important is that Justin is accepted and is a full-member of the church community. He is included in Sunday School activities and participates in the children's choir. There is no question that he will be involved. The sanctuary is wheelchair accessible, handicap parking is readily available, as well as accessible bathrooms and drinking fountains. The church has also created a fund to assist us with on going medical expenses.

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Well-intentioned, educated people still overlook children and adults with disabilities. Even in a church that values inclusive worship, the advocacy and education by parents and individuals with disabilities never stops. Parents and self-advocates cannot assume people will know what we need. We must tell them.

Is ours the perfect congregation? No. As long as human beings make up the congregation, it will continue to need to grow in its understandings of how to be an inclusive community. This does not come naturally. Parents and persons with disabilities need to be willing to teach.

For example, on Palm Sunday, our worship tradition includes the children leaving the sanctuary at an appointed time, picking up palm branches in the hall and reentering the church sanctuary singing while waving the branches. Traditionally, the procession moves up the steps to the balcony above the sanctuary. It is an inspirational service. When Justin first participated, he was 6 years old. I assumed the church staff responsible for the event would remember Justin could not go up the balcony steps (there is no elevator). Wrong. No one had thought about him. Justin wheeled himself over to our bench waving his palm branch while the other children all went to the balcony. It was hard for me to hold back the tears.

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Self-advocacy is a common term used by professionals who work with people who have disabilities. I'm supportive of self-advocacy, but I get tired. I advocate for my child at school, in the community, at church, and with doctors. How refreshing it is to have others join us in these efforts. It is appropriate that these be our brothers and sisters in our religious community.

My husband and I shared our hurt about the Psalm Sunday activity with the members of our small group from our congregation. One of the group members discussed this with the church staff. The Palm Sunday tradition was immediately changed and improved. Now, some of the children go to the balcony and some remain on the sanctuary level to wave their palms praising God. Such a small thing, yet a *tangible* statement of intent. This congregation proved it wants to be inclusive and wants Justin to be a *participant* in worship rather than an *observer*. Sharing our feelings raised the church leaders' awareness of the situation, which resulted in change.

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Many religions and denominations have created models to organize a supportive care network for people and families who have a disabled member. I've heard these called "Supportive Care Groups," "Circles of Friends," and "Friends of ... Clubs". I'm sure there are others. The goal each of these has in common is providing *intentional* support. They offer a way for a group of people to organize themselves around tasks and needs family and individuals with disabilities may have. I encourage you to check with your own church-wide office to see if they have some information available about this type of model. If they do not, borrow from another denomination.

I continue on the journey of knowing more about this God I worship. Each day I learn more. Having a son with a disability has been much of this learning. It has not been easy and is not the path I would have chosen, but it is a beautiful path. I close with this challenge from a woman who has a disability and was in attendance at a conference at Candler School of Theology:

"Don't you pray for my healing. Don't be presumptuous enough to assume in your prayers that I should become like you. Pray for yourselves, that you become aware of your own limitations as I have had to become aware of mine. Then we can become a community of faith."

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~ By Sheila Sopher Yoder

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