“I look into her eyes. Autistic people in general never look at you; they will always look down. Early on, Jennifer didn’t make eye contact, but later on in life she started to make eye contact. For me, looking into her eyes is like looking into her soul. I see a lot, I read a lot, I sense a lot. This might be the primary method of communication between me and this little girl, by looking through her eyes. Sometimes I will just sit down with her in a chair, she will sit on my lap, and I will just look into her eyes. I feel I am gazing into eternity; it is enormously joyful for me to do that.”—Carl, father of Jennifer, age 2.

Most fathers face challenges as they care for their children. Among the many fathers who face obstacles, some, like Carl, are the fathers of children with special needs. These children usually require more parental care and more community and institutional support. Until recently, scholars and practitioners often treated fathers as relatively unimportant to development of children with special needs. We know little about what fathers actually do in their involvement with their disabled children, but we know there is great diversity of experience because of variation in disabilities and fathering styles.

By exploring the ways fathers contribute to these children’s well being, we can help define responsible, involved fathering. We can also gain important benefits from reading the stories of fathers in challenging circumstances. When fathers share how they try to meet the needs of their children, they often describe aspects of fathering that may have been overlooked.

In my research, I have gathered stories from fathers of children with special needs. The stories presented are from highly religious fathers of children with a variety of serious disabilities and chronic illnesses. Because fathers work together with mothers in significant ways to meet their children’s needs, the study of married fathers is...
important. Researchers have found that highly religious fathers tend to be intensely involved with their children and are less likely than non-religious fathers to exhibit behaviors that harm children. Therefore, a study of highly religious fathers can provide examples of responsible fathering. Religious communities seem to help fathers better provide the social or family capital that benefits children.

This article shares and briefly analyzes the stories of fathers of children with special needs. Because each narrative is individual and the fathers in the sample are highly religious, these findings cannot be easily generalized to the population of fathers of children with special needs. However, the rich descriptions in the fathers’ stories allow us to become more aware of their range of experience and provide insights into fathering in challenging circumstances. And while not all fathers of children with special needs are as devoutly religious as the fathers we interviewed, research indicates that most fathers of children with significant challenges wrestle with questions of meaning: many try to find strength and support in some type of spiritual or religious belief, practice, or community. Their stories communicate the myriad considerable efforts that fathers often make when caring for a child with special needs.

**WRESTLING WITH MEANING**

**SIGNIFICANT INSIGHTS**

Significant insights that are highly valued by fathers are often part of the experience of fathering a child with challenges. Wrestling with meaning is an inherent part of raising a child with special needs. The following stories highlight this struggle.

A father of an autistic child said: “You don’t know what you are going to run into. You don’t know what great insights and blessings are going to come to you because you are devoting your life and your resources in a different direction than the one you anticipated. Your child may not go to college. She may never get married. But I am convinced that there is a plan for Marisa and we are a part of that plan. I don’t want to thwart the purposes of God by denying her ability to achieve all that she can achieve.”

Charles: “We did our best to make sure that we got through it well. We weren’t going to say, ‘Why me?’ and that is something I spent very little time on. I still wondered from time to time why she had to go through this, but I didn’t spend any time being mad at God that we were chosen to go through this. I decided early on that we were going to tackle this with faith and determination, and we were going to make it. We were going to come out being in love with God and not hating him.”

Ethan: “Bryce collapses in church and is back in the hospital. Back in the hospital again. I said, ‘Why, hasn’t he suffered enough?’ I was so tired of watching Bryce suffer and there was not a thing I could do about it. I remember walking around the hospital with my wife and sitting down and starting to sob. That’s when she taught me a great lesson, that ‘Heavenly Father loves him more than you do and he’s not going to do anything that Bryce can’t handle, so what’s your problem?’ She’s really candid about those things. That was a great moment. There have been lots of moments like that.”
He’s got some great talents, some great gifts. It’s just made me aware that, that I need to look at that and be aware of that in other people.”

Meeting demands through generative ingenuity

Good fathering of children with special needs requires flexibility, innovation, and creativity—what Sean Brotherson and I called generative ingenuity.8 The stories told in this section highlight some of the ways fathers use their minds and energies to meet their children’s needs.

Lewis: “I don’t think [my child having spina bifida] changes anything for me personally. Obviously it’s going to come into play later—I don’t think that he’s going to be a real hiker. But we’ll find ways to deal with that. I don’t think it’s going to have a big effect. He can still learn [to fish]. You don’t know me very well; I’d park in the stream if I have to. I’ve taken my dad out, and he can’t walk. I just say, ‘All right, you sit here in the truck.’ I drove up and parked in the stream, so he could fish. That was fun!”

Curtis: “When Matt was a year old he was talking like any normal kid. He was starting to say words and then all of a sudden there was nothing. We tried and tried to get his ears cleared up with antibiotics, etc., and it didn’t work. It was really kind of hard when you see other kids his age talking and communicating, and Matt would just sit there and do nothing. Physically he was fine. He could run and jump and throw. I thought, ‘Poor kid, he’s got to go through school and he’ll be behind.’ But then I decided he could catch up if we work with him, and so we’ve got to do it now and hold up our end of the deal. At first, it was kind of hard, but it doesn’t bother me now. I’ve seen him do [it] and how he can learn. He doesn’t have a learning disability, he’s just had a hard time hearing and now he’s got to catch up. Now, I’ve seen that it will work out.”

Steven: “When I first got this diagnosis of autism, the hope, the high expectations, the assumed success that your child is going to have in life, just sort of all drained out of me. I probably turned white as a ghost or something when the realization hit me that here’s this diagnosis—AUTISM. And it just sort of hits you like someone just swung a bat at you and knocked the wind right out of you. And so the first thing I would say [to a father in a similar situation] is this is not
a death sentence. There is hope here. And it is not just false hope and stay positive for your child. Our child has made enormous gains by getting some specific treatment for her and by taking an approach as a family, as a couple, as her parents, in dealing with her in certain ways, and helping her cope, and expanding her capabilities in other ways. So there is always hope. Quite frankly, as her father, I do whatever I can all the way around, making the best of the situation.”

DIVIDING LABOR, MULTIPLYING JOY

Fathers often reported working with their child’s mother to meet the needs of the child, drawing from each other’s strengths and preferences. The fathers also reported that there were some aspects of caring to which they brought essential individual strengths. Parents of children with special needs divide their tasks and roles according to their strengths, as opposed to gender norms. Those few cases in which fathers related experiences when only they were able to meet their child’s needs usually involved situations where the father’s physical strength was necessary.

Matt: “When Jennifer was young, she used to tantrum a lot, expressing her frustration and anger very physically. I used to pick her up and hold her close in an attempt to settle her down. Eventually I could wrap my arms around her and sit in a chair or something, partly to restrain her and partly to communicate to her the enormous love and caring I had for her. I am not sure if holding her is what calmed her, but it did. Laura couldn’t do the same thing that I could do, maybe because of my size, but I always felt from a very young age, that we had a bit of a bond.”

Jake: “Whenever I come home, if my son’s been having a bad day, I just pick him up and take care of him. He doesn’t always calm down, but I am the one that deals with it whenever I am home. We kind of joke about it, but he’s my kid. I stay up all night rocking him when he can’t sleep; when he’s screaming, having his night terrors, I just know him, I can just take care of him. I come home and he’ll be screaming and I can pick him up and make him a sandwich and help him eat it and he’ll calm down and go about his business, when he wouldn’t eat before that. Everybody knows he’s my kid and I take care of him. [Knowing that he needs me like that] is a tremendous pressure and great at the same time.”

Charles: “I have just about spent my life caring for and nurturing Rachel, when I wasn’t at work. Maybe the hospital is the part we’d like to forget but can’t. When her pain got to the point that she couldn’t go to the bathroom, I was the one that got her bedpans for her. She would only let me do it; I was the one that did that. It wasn’t a thing for Mom, and she didn’t want anybody else in the room. She kicked everybody out of the room—nurses, Mom (Mom had to be outside the door)—and I would get the bedpan as best as I could under her bottom without hurting her. Moving the sheets hurt her. It was not a good thing. But she let me do that for her, and I was able to take care of her needs, and it helped me that I was the only one
she’d let do it. You wouldn’t expect bedpan shuffling to be a wonderful memory, but it was. She trusted me to do my best job not to hurt her, and that was special to me that she let me do that.”

**Faith of Fathers & Children**

Research demonstrates that religion can provide great support for families with children with special needs. The fathers in our study also drew on their religious beliefs and faith communities to help them. Fathers also mentioned a connection between their religious involvement and a sense of responsibility to their children. The following narratives reflect the thoughts of many of the fathers who expressed that their religious commitments facilitated a greater sense of paternal responsibility and helped them to meet the challenging needs of their children.

Monty: “They [the church members] have been there. They were helpful to me when my son was in the hospital. I could call on them and depend on them to pick me up if I needed a ride home [because my car was broken down]. They [also] helped us with meals. It was great. It meant a lot to me. Here I had no transportation, my wife was at the hospital, and [we] could just call and rely on them.”

Chris: “[The doctors] kept working on [my daughter] trying to get her to breathe, and she was just lying there. They couldn’t get her to breathe, and this went on and on. That’s when I get hit with this mantle of fatherhood. [I] realize that she is new to this world, and her mom is lying on the table, has undergone major surgery, and you’re the only person in the world she has. There’s all the doctors, there’s everyone around, but when she’s in trouble, you’re the one she’s going to look to. You’re the one that has to be there for her. I just had to start praying for her. When she was in the most need it just hit me that it was up to me to pray for her. There was no one else on earth that could do that for her at that time. That was probably the most sacred [experience I’ve had].”

Michael, whose son was 9, told of his son’s religious perspective on his challenges: “[Thinking about my son with special needs,] I thought, life is not a beauty contest. Christ never said, ‘Blessed are the physically most beautiful, for they shall inherit the kingdom of God.’ You know, if you read the Beatitudes, they’re pretty non-physical; instead they have everything to do with the quality of our heart and our spirit. And Alan is an extraordinary individual. Alan has this natural ability to elicit love from people. We’ve flown all over the country, talking to physicians, and everywhere he goes, people like him, they act in godly, kindly, unselfish, genuine ways around him. Alan has an innate gift about that, and a real sensitivity about spiritual things. One time he and I were alone in the kitchen and he looked up at me and said, ‘You know dad, if I were born again, I would like to have hands like Kathleen and like Benjamin.’ And I didn’t say anything for a moment, and then he said, ‘But this is just the challenge that Heavenly Father has given me for this life.’ And he paused again, and then said, ‘So it’s okay.’ But it wasn’t a mournful okay, it was...
kind of a ‘this is all right’—almost like a little bit of spunk and possibly even enthusiasm in the tone, ‘This is all right; this is just my challenge.’

CONCLUSION

The stories told by fathers of children with special needs show responsiveness to their children’s increased need for fathering that is intensely involved in their particular challenges. Their experiences are examples of the creativity and strength needed to build bonds of love with children who need greater involvement and care. For fathers, the stories can inspire increased attention to the ways each child requires a father who will respond to his or her needs.

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References

1. The children in this study suffered from developmental delays, autism, Tourette’s syndrome, Down syndrome, hearing, speech, and vision difficulties, heart disease, birth defects, scoliosis, seizures, respiratory problems, and other difficulties. Names of the fathers and children have been changed.


4. All the fathers were active members of The Church of Jesus Christ of Latter-day Saints.


8. S. E. Brotherson & D. C. Dollahite (note 1, above, 1997).