We share a few things we have learned from our experience with Dora, our daughter with special needs, hoping and praying that our thoughts and words may bless someone else who is on a similar journey.
In the days that followed our daughter Dora’s scheduled birth by Caesarean section, we knew that something was different about her. But it was not until she was rushed directly to the hospital from a doctor’s checkup three weeks later that we began to understand what a life-changing event her birth would be for our family.

The weeks and months that followed took us on a roller-coaster ride of hopes and fears as dedicated professionals tried to diagnose Dora’s condition. Each new theory brought its own set of anxieties.

“Oh please, not that. We could not bear to lose her,” we responded to one possible diagnosis. “If it is this, we are not sure how we can deal with it,” we responded to another.

Diagnosis is a two-edged sword. It can bring closure and help one understand what the future may be like, but it can also create expectations or define limitations that may not even be real. In our case, we are grateful that after all the theories and tests, doctors could never come to a specific diagnosis for Dora.

“She is physiologically normal in every way,” they told us, “but she suffers from low muscle tone and seizures.”

We have lived the past 28 years with that statement—its uncertainties, its twists and turns, its challenges, and its joys and possibilities. We did not know what the road would be like, but we never felt limited by a specific medical diagnosis.

We love to define Dora by her abilities rather than by her limitations.
Defining a Person with Special Needs

Some of the most frequent questions we have received over the years about Dora are “What does she have?” and “What is her disability?” We generally answer by saying something like, “Well, she doesn’t talk, walk without aid, or feed or dress herself, but she is so much more than that.”

We have learned not to define her by her inabilities or her limitations. Rather, we love to define her by her abilities. For example, Dora can smile. Her smile makes those around her smile. Total strangers have stopped us in the airport to ask if they can take a picture with Dora simply because they have been overwhelmed by the light of her radiant smile.

She can give hugs. If you are lucky enough to get a hug from Dora, it will change your life. Once, when we were walking out of a sporting event, Dora passed a homeless man on the sidewalk and spontaneously reached out and hugged him. It was obvious from his expression that her hug was one of the most amazing things he had experienced that day.

Dora helps you feel loved. If Dora locks eyes with you, even for a second, you will feel a love and sweetness that might cause tears to well up in your eyes. With those amazing gifts, why would we ever want to define her as “disabled” or “handicapped”? She has influenced hundreds of lives for good simply by being who she is and doing what she does.

One Day at a Time

It is easy for parents to become overwhelmed when they realize that their child will depend on them for a lifetime. Feeling overwhelmed is even more pronounced when that child requires constant physical, emotional, and perhaps medical support. The prospect of feeding, dressing, bathing, caring for, and supporting a child every day can appear as a mountain that is just too tall and steep to climb.

In those moments, it is important to step back and say, “I just need to do this today.” We have found that by focusing just on the needs and opportunities of each day, the task seems more manageable. We can live just one day at a time, and we can look for the joy and growth that come with that day.

FRAIL FRAME, DIVINE DESTINY

“A perfect body is not required to achieve a divine destiny. In fact, some of the sweetest spirits are housed in frail frames. Great spiritual strength is often developed by those with physical challenges—precisely because they are challenged. Such individuals are entitled to all the blessings that God has in store for His faithful and obedient children.”

Capable of Enlargement

Each spirit sent to earth is capable of "enlargement." All of us are expected to exercise our agency to the degree that we are able. We caregivers are responsible to help those under our care to grow and progress physically, emotionally, and spiritually to the extent they are able. That can mean helping them to have opportunities to serve—such as Dora giving hugs or smiles. It can also mean helping them to use and, if possible, enlarge their physical and mental capacities through therapy and activity.

In doing so, we need to be realistic. If we are constantly frustrated, we may be pushing too hard. The Lord can help us and guide us through His Spirit to do those things that are possible and appropriate. In some cases, He will give us miracles, small as they may seem.

We will always remember being told by a leading orthopedic specialist that Dora would never walk. But after several years of much prayer and hard work, Dora can now walk with assistance. Her overall condition hasn’t changed, but the Lord gave us a small miracle to help her grow and find more enjoyment in life.

Faith Not to Be Healed

It is only natural to ask why when a precious, challenged child of God is sent to our home. Our faith naturally leads us to ask God whether it would be possible to heal or remove the child’s condition. We have the certain faith that God can heal our daughter, but He has also made it clear that it is not His will to do so now.

Heavenly Father has His own purposes for sending Dora to us, and He will heal her—if and when He wills to do so. That day may not come until the time of ultimate healing—the Resurrection. It takes as much faith to accept God’s will that these precious ones not be healed now as it does to believe that He can heal them now. Dora was sent to us with a purpose, and we have felt cautioned not to seek why but to ask Heavenly Father what He wants us to learn.

“To ask, Why does this have to happen to me? Why do I have to suffer this, now? What have I done to cause this? will lead you into blind alleys,” said Elder Richard G. Scott (1928–2015) of the Quorum of the Twelve Apostles. Instead, he said, “Ask, What am I to do? What am I to learn from this experience? . . . When you pray with real conviction, ‘Please let me know Thy will’ and ‘May Thy will be done,’ you are in the strongest position to receive the maximum help from your loving Father.”

At times we think of the parents of those children the Savior healed during His mortal ministry. Perhaps, like us, those parents wondered for what purpose their children were sent to them. After the Savior had healed them, the parents could understand that it would have been impossible for Him to demonstrate His healing power and divinity had there been no one to heal.

We have the faith that a time of healing will come for all of God’s children.

We look forward to that day.

NOTES

1. The Prophet Joseph Smith taught, "All the minds and spirits that God ever sent into the world are susceptible of enlargement" (Teachings of Presidents of the Church: Joseph Smith [2007], 210).