



Clayton's Story

As we anxiously awaited the birth of our first child, my husband and I had so many thoughts racing through our minds. What disability he would be born with was **not** one of those thoughts. Denial was not the problem; we simply never considered anything would be wrong with the health of our beautiful baby boy. The following morning after Clayton came into our world, the doctors gently (if that is at all possible) informed us our newborn baby had three heart defects that would require surgery, and that the defects were caused by his being born with Down syndrome --- WOW!

Instead of feeling that special sense of joy, all those months of waiting ended up with our world turned upside down. The baby we had been waiting for never arrived. Shock was not the word to describe the state of mind we were in. It was a couple of weeks later after we finally arrived home from the hospital that I read the sensation of grief we were experiencing was completely normal. We felt horrible for feeling this way. After all, **we** did not have Down syndrome, Clayton did. The thought of not knowing what was in store for us was utterly frightening. All I knew was that we needed to find out as much as we could about Down syndrome so that we could start helping our little Clayton. The love for our little baby and loving family support strengthened us to do what we had to do, to hold on tight through our emotional rollercoaster ride. Literally overnight we had to become experts on a syndrome we knew nothing about and all the medical, emotional, and financial issues that accompany it.

In our quest for knowledge, we found out about a state run program - Early Intervention (Infant-Toddler Program) that was put in place to specifically help newborn to three year olds like Clayton. Our family was referred to Colorado Bluesky Enterprises, Inc. (local program) by the hospital where Clayton was born. At the time we had no idea how the program and the people involved would turn our emotional rollercoaster from frightening to fun. We found out they could provide our family and Clayton with a variety of amazingly helpful services from his birth until he turned three. Their services were provided primarily in our own home where Clayton was most comfortable. While having our therapy session with an infant teacher once a week we learned how to help him develop his gross and fine motor skills, speech/language, social skills, problem solving and reasoning, and self-help skills in surroundings Clayton was used to. It is crucial that all of these areas are stimulated very early on to improve developmental outcomes, hence the name

Early Intervention. We even had a case manager to help our family make decisions about the type of support we needed, as well as assisting us in securing that support.

Throughout all of this irreplaceable and incomparable help, not a penny was asked of us. Financial strain was already creeping in after Clayton was born, and to find out all of this help was going to be no charge to us was an unexplainable heavy burden lifted off our shoulders. Everyone involved with the program proved they LOVED and cherished what they did for a living. They viewed every life they worked with as if they were their own children. I have never seen a group of people show so much love, enthusiasm, confidence, comfort, and support. By showing all of these things to our children and their families, they instilled in us a solid foundation on which we can continue to help our children for their lifetime. For that we are eternally grateful.

Following is an illustration written with the intention of trying to explain what the preceding few lines truly mean:

It was as if our plane had crashed into the sea by a deserted island leaving us dazed, confused, and scared beyond belief. From the jungle came a smiling face, a caring heart, and a warm embrace showing us the way. Taking our hand to lead us in a fearful unknown land, Colorado Bluesky showed us that we would be ok. Helping us to see that our journey is one that is shared by others, we soon realized it wasn't a bad one - just a different one. Little did we know our new home held many unforgettable experiences leading us to become better people and gain lifelong friendships along the way. Blue Sky taught us to feel the abundant warmth from the sun, to turn around and see how wonderful the water that we almost drowned in really was.

I once read the child with Down syndrome will reveal a dimension of spiritual and emotional tenderness that are all too often hidden for most of us under the pressures of modern life. Clayton is now two years old. His presence in our lives is profound. He has touched the hearts of more people than we could ever imagine.

Who knew the baby we were waiting for - only better - was right in front of us the whole time.

Written by
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