A Personal View on the Church and Children with Special Needs by Holly Fletcher

Though my Papa was disabled and I went to Sunday school the first 10 years of my life with a special needs child, children and adults with special needs in church have always been on the periphery of my consciousness—that is until my daughter, Maddy, was born. With her birth, the issue of how individuals with special needs are served (or not served) by churches, riveted my attention.

In 2009, the lives of my husband, Aaron, and I were radically changed. Our precious daughter, Maddy, was born with an idiopathic, congenital condition called arthrogryposis. Arthrogryposis effects the tendons and joints. Children may be born with arms and legs in an extended position with inability to bend joints or, like Maddy, they may be born in a flexed position with limited ability to extend joints. Arthrogryposis is fairly uncommon, and the range of its effects is on such a spectrum that it is really impossible for doctors to predict how a child will develop and what their level of functionality will be as they get older. Arthrogryposis rarely effects cognitive ability and it is not progressive, so most individuals with the condition are able to live full and fairly normal lives. I would say that Maddy falls within the moderate range of the condition.

Maddy has made amazing progress over the past 4 years of her life and she is able to walk independently. However, her knees are still flexed at about 25 to 30 degrees and she had very limited mobility in her wrists and various amounts of mobility with her fingers, which extend to different ranges. For example, the middle finger on her right hand has limited extension and she is not able to fully extend her tendon between the forefinger and thumb on her left hand because of the tightness of the skin. Because she was born with her fists closed, the webbing between finger and thumb did not keep pace with her growth and is now restricting her extension. Despite these limitations of range and motion in her hands, she has always kept pace with average development for her age in fine motor skills, thanks to some great occupational therapists, to her dad’s determination to splint her hands at night, even when doctors told him there wasn’t a way or she was too small, and to the grace of God.

I share these details of Maddy’s condition so that my discussion of her needs and of obstacles we’ve faced regarding church, Sunday school, and finding a faith based pre-school can be clearly understood. I also share them because each special needs child has different levels of need and will require different accommodations accordingly. What I have to say is just an illustration of issues that families with children with special needs might encounter. It by no means encompasses or even illustrates every family’s experience when seeking a church home or pre-school or school for their special needs child.

My husband Aaron completed his Ph.D. in Biochemistry and Cell Biology in May 2007 at Colorado State University. In August 2007, we moved from Colorado to Dallas. In Colorado we were no more than 6 hours away from any immediate family members. Both my sisters lived in the same town as us. Now we were 730 miles or a 13 hour drive away from most of our family. After a few false starts with work, Aaron began a post-doc at UT Southwestern and we found a church family.

In June 2008, we left the church we had been attending and joined a small Baptist Church in Dallas and my husband, Aaron, accepted a position as a biology professor at Dallas Baptist University. He began his first semester of teaching in August of 2009 and I went back to school at DBU to pursue my MLA with an emphasis in English. On top of all of these life changes, we discovered that we were pregnant shortly before the Fall semester began. Though nervous and a little stressed, we adjusted to all the changes and we were excitedly anticipating the first sonogram to find out the sex of our baby. We were overjoyed to
see our little girl on the screen at the sonogram. The technician seemed somewhat brisk and unfriendly, but we brushed it aside in our excitement of seeing our daughter for the first time. On returning to the doctor’s office, our doctor called us into his personal office. He proceeded to tell us that the sonogram had detected some very serious issues with our baby. Her legs and hands were not formed correctly and it appeared that her heart was not formed correctly and that she would not survive outside the womb. He referred us to a specialist and made an appointment for the same afternoon. We were devastated.

At the specialist’s office, we found out that the doctors suspected that our baby had Trisomy 18, a chromosomal disorder that results in 100% fatality. Many babies with this disorder will die in utero. If they survive to birth they will live only a few minutes to a few days after they are born. Usually, Trisomy 18 also causes holes in the brain. The doctor did a very thorough sonogram to examine Maddy’s head. He could find nothing abnormal. This was the first flicker of hope. He recommended an amniocentesis to check for chromosomal disorders. He also stressed that we needed results quickly because I was already 20 weeks pregnant. In Texas, if we desired to get an abortion, we could not get one after 24 weeks. He referred to Maddy as “the fetus” during the entire appointment. Fortunately we had a strong family and God had provided an amazing support system through DBU and through our small group at our church. I can only imagine the pressure and temptation a family who is pregnant with a special needs child would feel to have an abortion or to rationalize an abortion under these circumstances without these support systems, yet many who go through this are not attending church or don’t have strong connections within their church family. Even with our strong support system we went through a major crisis of prayer over whether we should risk going through a pregnancy to full term with a baby who would not live past birth. However, we also knew this was not a decision to be made without the results of the amniocentesis.

I remember being in the DBU library studying when the call came from the doctor’s office to tell us the results of the chromosomal screen. I could not answer the phone. I left the library and walked over to Aaron’s office so that he could call them back and hear the results with me. Amazingly, the screen reported that there were no chromosomal disorders detected. However, there was an anomaly of extra genetic material on chromosome 15. The doctors suspected that this was not a big deal, but had Aaron and I both give blood samples to check our chromosomes. After more nervous waiting, the news came back that this anomaly was on Aaron’s chromosome 15 as well, so the joke began that Maddy would be no weirder than he was. Though we were very relieved that there was not a chromosomal disorder, we still had a long road to travel to find out what was going on with our baby. Our next step was to see a pediatric cardiologist and a geneticist.

The pediatric cardiologist was wonderful. When he came into the room to discuss the results of the sonogram on Maddy’s heart, the first question he asked was, “What is your daughter’s name?” His validation of Maddy as a person was priceless encouragement to us. He told us that the heart was turned at an angle and that some of the “plumbing” was small and underdeveloped. We were then sent to Children’s Hospital in Dallas to undergo an MRI for them to look at her heart. The results of the MRI did not have any significant finding of serious issues with Maddy’s heart. We also saw a geneticist during this time. The geneticist diagnosed Maddy with arthrogryposis, a very hopeful and positive diagnosis for parents who had been told two weeks previously that their child had no chance of surviving. Our church family continued to support us and pray for a miracle with us as we continued to search for answers about Maddy’s heart—the last piece of the puzzle to what exactly her issues would be. Upon our second visit to the cardiologist, he informed us that the sonogram showed normal heart development and
normal size. He said that if we had walked in off the street he would have had no reason to think our baby was not developing normal just by looking at the sonogram of the heart. We were blown away! We and our families and church family believe that God did a miracle to heal Maddy’s heart.

None of our doctors could offer an explanation for why her heart wasn’t normal and then it was. The specialist who had informed us about quick action in order to have the option of abortion had nothing to say. He basically ignored the occurrence and continued to do routine sonograms to monitor Maddy’s growth. We also did weekly stress tests to monitor Maddy's heart. The stress tests continuously showed a strong and regular heartbeat.

Now we were very hopeful for Maddy’s future. Our church and DBU family continued to show strong support for us by being flexible with Aaron’s work schedule to allow him to attend doctor’s appointment and through prayer. The day of Maddy’s birth finally came. I had been worried about being repulsed by Maddy’s appearance at birth and worried that I wouldn’t love her after I saw her. All of these worries were vain. It was love at first sight for both Aaron and I. Maddy was born in the fetal position and stayed their unable to extend her arms or legs. Her birth record says she was 15” at birth because they could not stretch out her legs to measure her. She had a beautiful, full head of dark hair and her cry sounded like a little lamb bleating. Many people from DBU and our church family came to visit and celebrate the birth of the most beautiful baby we’d ever seen. Maddy spent two weeks in NICU for feeding issues and many from DBU and our church brought meals during this time.

Finally the day of bringing Maddy home came on a rainy Easter Sunday. We celebrated her homecoming and Easter with a lunch of Subway sandwiches. It was the best and most memorable Easter we’ve ever had. This also began the adjustment and journey of coping with a new baby as well as multiple therapy and doctor’s visits every week. Thanks to a connection to Scottish Rite through one of the members on the Board of Trustees for DBU, we were able to get Maddy into Scottish Rite when she was three weeks old. For three to four months we went to Scottish Rite every Friday for casting on her knees and club foot. We began weekly therapy appointments. During Maddy’s first year, we also discovered that she had some hearing impairment. This added a whole new aspect of issues and treatment. We saw various other doctors to follow up on other issues and concerns connected to her condition. At one point in time Maddy had a total of 11 different doctors and juggling all of the visits was quite a challenge. Between her appointments and my school work (I did not give up on getting my MLA and graduated December 2010), there was no time for play dates or mom’s groups. Our main sources of support continued to be our church and DBU family.

For the first six months, I did not feel comfortable leaving Maddy in the nursery at church. Part of this was because she was still eating poorly and part of this was because I did not have the assurance that the nursery workers would understand how to take care of her with all of the casting, splinting and feeding issues we were dealing with at the time. However, as Maddy grew and became more interactive, I felt more comfortable leaving her for short periods of time. The nursery work, Miss Elizabeth, turned out to be an incredible blessing and an amazing prayer warrior for Maddy. Miss Elizabeth would spend a large amount of her time rocking Maddy, singing to her, praying over her. She would declare to us each time we picked Maddy up from the nursery, “I pray for her to walk. I know she is going to walk.”

When it came time for Maddy to move up to the toddler room, we began to work through the collision of our perceptions of her abilities with the perceptions of her abilities by the pre-school program
director. Our pre-school director is an amazing lady who has worked hard to create a wonderful program. However, our church is small and resources are sometimes limited. This is a disadvantage. The advantage of a small church is that everyone knows you, knows your situation, and there is a lot of love to cover over disagreements or misunderstanding, a lot of room to discuss, improve and grow. When Maddy turned one, our director did not want to move her up to the toddler room. She was afraid that Maddy, who was just beginning to crawl at this age, would get run over by other rambunctious toddlers. Aaron and I wanted Maddy to move up because we knew that cognitively she needed to begin to have more structured Bible learning time and she needed interaction and challenge from peers her own age. At the same time, we didn’t want to insist on the toddler room worker being put into a situation that she was not comfortable with or to have Maddy take so much focus away from the other kids that they weren’t getting the attention they needed. So instead of insisting that Maddy be moved up right away, we decided to wait for several months. If the director did not move her up by the fall, then we would insist that she be moved up or we’d start looking for another church and a kid’s program that could accommodate Maddy. Thankfully, after a few months, some of the older toddlers moved up to the next class and Maddy moved into the toddler room. She was with two other children who had been in Sunday School with her since she was a baby and it is amazing to see how kids, accept, adjust to, and watch out for each other’s needs. Instead of running over her, they ran around her.

Maddy took her first steps at 28 months. She began using a walker to help her walk longer distances. As she became one of the older toddlers in her Sunday School class, even though she couldn’t walk as well as some of the younger toddler’s in the class, I would look in and observe her assisting the younger toddlers. One day I watched as the class ate snack. One of the younger children dropped their paper cup on the floor. Maddy reached down and snagged the paper cup with her little fingers and sat it back on the table for the other child.

As Maddy neared the age to be moved up to the three year old class, we went through another rough transition of the pre-school director not wanting to move Maddy and us wanting her to be moved because we knew she was bored in the toddler room and needed to be mentally challenged by more complicated Bible stories and activities. As Maddy begin to act out by teasing, pushing, hitting other children, and taking toys for others, the pre-school director came to the realization that we were right in our estimation of her need to move classes. She moved Maddy to the three year old class and the acting out ceased. Despite the director’s worries that Maddy would get run over by the other children, this was never a problem. Maddy was adaptable and aware enough of what the other children were doing to take care of herself and the other children, again, went around her instead of over her.

At the end of the school year, I decided to explore the option of putting Maddy into a faith-based pre-school or Mother’s Day Out program for a couple of days a week. This had been strongly recommended by some of her doctor’s as they thought it would be good for her to be challenged physically to keep up with other kids as well as a good thing for her social development. I began searching for pre-schools and MDO programs online as well as getting a list of school’s from Maddy’s developmental pediatrician and some recommendations from Maddy’s dietician who had several children who’d been involved in MDO’s in the area. Both Aaron and I are from small towns so we felt more comfortable looking at small programs. This turned out to not be such a good plan.

When I began looking at schools, Maddy was consistently using a walker to get around. She was potty training but was not fully potty trained and she was still wearing pull ups. Many MDO’s and preschools
won’t accept 3 year olds who aren’t fully potty trained. So that eliminated several schools for us without tours. I imagine it eliminated a lot of kids both special needs and non-special needs as well, but I won’t get started on that. Anyhow, we finally found a pre-school that fit our price range that did not have this requirement that was fairly small, and close to our neighborhood. We scheduled a tour and I took Maddy over, walker and all. Though the teachers and directors were very kind and gracious to Maddy and interacted with her very well, I could see the fear in the eyes of the program director. A special needs child, even one as functional as Maddy, was out of her league. From looking at the school and how it was set up (all one level) I felt that Maddy would adjust well to their program. I sent the director a list of accommodations Maddy might need: using her walker, assistance going potty, perhaps some restrictions on the playground. The director called me back and suggested that I look into the five day a week public school Head Start for Maddy. We had already looked into this and Maddy did not qualify according to the school’s standards because her language development was normal. All I wanted from this director was a straight answer as to whether she was comfortable accommodating Maddy at her preschool. If she would have just said, I don’t think our program has the resources to accommodate your child at this time, I would have understood. Instead I got untimely and unsolicited advice that came off as an indirect questioning, even criticism of my parenting abilities and the decisions we were making for our child. This left a very bad taste in my mouth for this particular program and church. At this point I decided to call the biggest church I knew of in our area: Prestonwood Baptist Church. I figured if they didn’t have resources to accommodate a special needs child, then I might as well give it up.

Maddy and I did the tour of Prestonwood and received a warm welcome. The MDO program there had had several special needs children, some in wheelchairs, go through their program. The director of the program, Michelle Pinkston, not only assured me that they had the resources to accommodate Maddy and her needs but that they also had the desire. Michelle explained that not only could they be a blessing to Maddy, but that Maddy would be a blessing to their program. On that note, it was decided.

Maddy would attend CLC in the fall.

As a trial run, I enrolled Maddy in VBS. I had a meeting with the director of the Special Needs program at Prestonwood. (Prestonwood has been focused on serving special needs for 20 years and has an array of resources for children and adults.) I wasn’t sure, because of Maddy’s walker, if she should go to the special needs VBS or regular VBS program. The special needs director listened to what I had to say about Maddy’s abilities and needs, watched Maddy play, talked to her, and determined that because of her cognitive level, she would be happiest in the regular VBS program. The special needs director and the director of VBS worked together to find Maddy a classroom in her age group with a teacher who would be comfortable with special needs. This was necessary since the VBS classroom staff are mostly volunteers.

Maddy had a very memorable week of VBS. The special needs director assigned a teenage volunteer to help her one on one in the classroom. The kids did a lot of moving around and walking to different areas away from the classroom so the volunteer was mostly there to help Maddy get from one place to the next. Maddy still asks about VBS all the time and is ready to go again to this summer.

Maddy has also had a wonderful year of MDO at Prestonwood. She goes twice a week for 5 hours each day. By the time school started, she had progressed so much with her walking that she did not need to use the walker as I had thought she would. She had also made a lot of progress with potty training though she still occasionally had accidents.
Maddy did have some struggles adjusting to walking so much at school. The day’s schedule requires each class to go to the playground, chapel, and ROMP (a combination of music time and PE). They also sometimes take trips to the library or computer room. Most of these activities are located on different floors so the children have to walk stairs. Stairs are very challenging for Maddy and there was a point where she did not want to go to school for several weeks because she disliked the stairs so much. However, I discussed the issues with her teacher and her teachers patiently worked with her to figure out a way to help her more on the stairs. They were also extremely patient and helpful as she adjusted to being self-motivated to go potty at school. I think the first couple of months in regards to the potty issue were rougher on the teachers than on Maddy, but we all stuck with it and made it through.

The program has been excellent for Maddy in every aspect of development. She now looks forward to school each day and has developed more physical endurance for walking longer distances. The kids in her class all look out for her, pray for her, and include her in their activities. The teachers are kind, loving, affirming and expect her to meet the same standard of behavior as the other children.

As Maddy grows, changes schools, and gets involved in extra-curricular activities, many of the challenges I’ve described above will be re-faced, revisited and re-evaluated. I’m confident that we will work through and meet these challenges, one step at a time. However, my confidence doesn’t come because I’m super women or I’m so great at figuring things out. I have confidence because I know that God is working in Maddy’s life and guiding her steps. I am also confident because I have the support system of a church family who loves our family and who is praying for us and for Maddy. While I feel incredibly blessed by this, it also makes me sad when I think of all the families with children with special needs who don’t know God and who don’t have the support of Christian brothers and sisters because I know that Maddy would not be where she is today without this support and that our family would not be where we are today without this support.

Having a child with special needs, no matter the need or the severity, is no picnic. There is extra stress in every level of life. Time gets eaten up with therapy and doctor appointments, money gets eaten up paying for the therapy and doctor appointments, marriages get stressed, parenting abilities and resources are used and tested to the limit, often relationships are limited and tested because parents don’t have as much time to cultivate and keep up with friendships as they used too.

We are very blessed to be financially stable. Aaron works full time at DBU and does some consulting on the side. I have been an adjunct in the English department at DBU since 2011. I am blessed to work on a very part-time basis and have lots of time to meet Maddy’s needs and get her to her therapy appointments. However, we haven’t been without financial stress. Even with great insurance, our medical expenses per month (including insurance payments) are roughly equal to our monthly mortgage payment. About 2 years ago, Aaron temporarily lost some income from a second job he was holding in addition to DBU. This resulted in some tight months and we also dropped dental insurance for everyone but Maddy. Fortunately, I’ve never had a cavity, so I wasn’t too worried about going without dental insurance for a year. Many families are not so lucky. Many parents both have to work full time to pay for medical expenses.

We have also had times where it has been difficult just to keep up with the daily business of life. With Aaron working full-time, plus consulting, my part-time work, and Maddy’s schedule, it’s sometimes difficult to get things like simple weekly lawn maintenance done. This has especially been true during times that Maddy has been recovering from a surgery. Again, Aaron and I are very energetic and
physically healthy and we work through this. There are families who have special needs children who place much more of a demand on time, energy, and resources than Maddy does. Not all parents of special needs children are blessed with good health themselves. Many families struggle to prepare healthy meals, get the house cleaned, and mow the lawn. For some getting out of the house to the store is nearly impossible.

All of these stresses come with having any child, but they are greatly exacerbated for parents of special needs children. Without a strong relationship with God and with a church family, how do families with special needs children make it? I don’t think they do make it. I believe far too many marriages are falling apart, far too many parents are stressed, depressed, and taxed beyond their emotional, physical, and financial limits. While the school system offers a variety of resources for therapy and preparation for school for special needs children, I think the resources to help parents spiritually, financially, and emotionally are often lacking. This is an opportunity for the church to step in to fill the gap.

When I think of parents of children with special needs, I’m often reminded of Hagar’s conversation with God in the desert when she ran away from Sarah. She believed that she had no place to go, that she did not belong anywhere. Then God sent an angel to let her know that He knew she was suffering. Hagar remarked that God was “the God who sees me” (Gen. 16:13). Many families with special needs children feel invisible. Without connection to a community it is easy for them to believe that no one understands what they are going through or where they’ve been. Often this is too true. The church doesn’t dislike families with special needs. It’s not even that the church doesn’t care. The church just doesn’t see them. This is the time and the opportunity to be “the God who sees me” to so many families that are struggling with life’s questions of suffering. This is the time to answer their question that if there is a God, does he care about my child too. We need to be God’s eyes that see these families and their needs.

So how can the church reach out to parents and children in special needs families? I’m definitely not an expert on organizing special needs ministries in churches. However, I do have some ideas from my personal experience about how even small churches can serve these families and show them they are loved.

1) Churches need to let families of special needs children know that they are wanted.
2) We need to have obvious and easily accessible counseling and support in place for families before their child is even born.
3) We need to let them know their child is valued and loved and will have a place in a community when they are born.
4) Churches need to organize events that are particularly designed for children with special needs and invite all families within the church to participate in the activities and welcome special needs families and their children.
5) Churches need to be honest about the resources they have to accommodate special needs children.
   - If resources are too limited, then churches need to have a network with other churches so that families don’t get lost.
   - We need to be able to say, “Our church is small and I’m so sorry that we can’t accommodate your child but I know the director of the children’s program at another church that can accommodate you. I will get you connected with them.”
6) We need to be willing to help families financially. Even if a family appears to be doing okay, they made need help.
7) We need to offer help and not wait to be asked.
8) We need to have counseling available for parents and for special needs children.
9) We need to be the friends who will volunteer to watch their child so that a parent can have some time for themself.
   -This may mean having a group of volunteers who get certified for CPR or doing trainings for specific special needs like autism.
10) In marriage and parenting classes and seminars we need to include sections on the special challenges of maintaining strong marriages and unique parenting challenges when parenting special needs children.
    -This will not only help families with special needs children, but it will bring awareness and understanding for parents who don’t have a child with special needs.
11) Children in the church need to be taught and trained by parents and Sunday school teachers to respect, value, and include children with special needs as part of their church family and to treat them as friends.
12) Finally, parents of and children with special needs need to be seen as not just someone to serve but as valuable servants who will add an extra dimension of understanding, compassion, and benefit to the church family. Families of children with special needs have been absent and invisible from church pews for too long. It is time to open our eyes and see them.