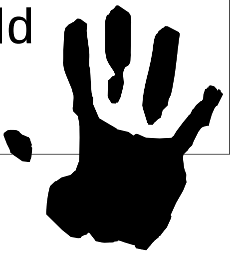
Creations of GOD Impacted by Disability:

One Mother's Thoughts

By Janet Lacher

"...let us look upon [Michael] as a creation of God. Let us look at God's fingerprints on a being with an eternal soul that is worth more than all of the possessions in the entire world. "

"It was about one and a half years ago, with skid marks across the threshold and finger indentations on the doorframe, that Mark and I were thrust through the door into the world of disabilities."



Dear Church Family,

In November of 2002 at age 7 months our youngest son, Michael, was diagnosed with infantile spasms. It is described in the medical literature as a catastrophic form of epilepsy. Michael began his workup on his first hospitalization and was discharged on a cold, clear, sunny Thanksgiving Day. That afternoon, Mark and I sat in stone silence in our living room, as we gazed upon Michael in disbelief that there was something very wrong with our precious baby. Over the course of the following year, we went through an extensive workup to identify the cause of Michael's seizures. We tried different treatment options that included medication after medication and a special diet in an attempt to control his seizures, all without success. On February 18, 2004, Michael underwent surgery to remove three lobes of the left hemisphere of his brain, and he also had his two hemispheres partially separated. The intended goal of surgery was to control seizures to a point where Michael's development could go forward. Currently, it seems that we have changed his relatively flat developmental trajectory in a positive manner, although we still do not have control of his daily seizures. All this to say by way of introduction, that I am not a veteran mom of a child with disabilities as some members of our congregation are, but I have spent a fair amount of time talking with other parents on 7940, the Pediatric Epilepsy Unit at St. Paul Children's Hospital. I have gained a small understanding of what it is like to dwell in this world.

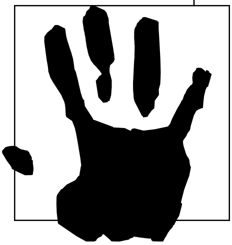
There are at least four major issues that parents of disabled children experience. While I do not think that these issues are unique to us, I believe that it may be helpful to the church to be aware of them. If one member of the body is hurting, the whole body is hurting.

The first issue is one of ongoing loss. With each developmental stage, a parent is confronted with new circumstances, and the reality of the disability presses and presses and presses on a parent. Then there is grieving. I think that the depth of the loss depends on the disability and the expectations of the parents. Regarding our situation, we do not know if Michael will be able to walk or talk or even understand language. We hope that his brain will rewire enough to do these things.

The losses not only involve a child's health but there are losses in how you view your family, and expectations of what your family should be like. There are changes in life style. With Michael, there is no "quick, going out the door." For him, three things are certain to bring on seizures: getting sick, missing a nap or not getting good sleep, and any type of stressor. All of these have implications for family life.

Another loss includes the loss of privacy as social workers, therapists, and different people come into your home to help. I am grateful for any assistance, but there is a tug-of-war that I experience as I learn to release these different areas. It takes a lot of energy to process these losses.

The second issue is one of fear. This varies from individual to individual or couple to couple, depending on the situation and a person's bent. Fears can range from financial, to what the



future may hold for the child and the family. There may even be fear of abandonment with the perception that people may grow weary of ongoing needs. I personally do not spend a lot of time thinking about these items. However, I do struggle with the fear of injuring myself while lifting Michael, especially since I just recently re-injured myself. As he continues to grow, it is harder and harder to lift him off the floor. I take these items to my Lord's feet and trust him with them.

It leads me to the third issue, which is the "nuts and bolts" of dealing with a child's disabilities from day to day. How do I manage a child like Michael who could consume all of my time with therapies and medical oversight, *and* manage the needs of three other children, *and* manage a house, *and* manage work (I have the health insurance), *and* have enough energy to invest in a relationship with my husband? There needs to be equilibrium in doing it.

The fourth issue involves the myriad of decisions that must be made. The decisions may be huge, such as removing part of a child's brain; or they can be relatively minor, such as adding another weekly therapy session. Navigating through the health care system and all of the government programs can be overwhelming. What might be best for Michael may not necessarily be best for the family. So how do you come to a balance and rhythm with it all? We are currently trying to establish a mission statement for our family with a few broad goals to serve as a compass in aiding us in our decisions. There is a wrestling and grappling in dealing with all of these decisions.

Each of these issues can be difficult by itself, but they are interwoven which makes them more complex. The ongoing nature of Michael's situation is daunting, but we are not without hope. What seems impossible to us is possible with God. His mercies are new every morning. I have seen his faithfulness even when things do not go the way we want them. I am trying to cultivate an attitude of thankfulness, lest I get sucked down into the tar pit of despair. I claim the hope that is in Christ, trusting that he will work this out for our good, even if Michael's health deteriorates. When Michael was in the hospital after his surgery, he was sleeping in his crib; I was looking at his big, swollen head with the 40 plus staples, and God led me to John 11 which talks about the suffering and death of Lazarus. Even though there was great suffering and grief by Lazarus and his family, Jesus told his disciples that he was glad for their sake so that they would believe and that it was for the glory of God. Meditating on this passage and others, gives me hope that Michael's suffering is not in vain. I also take comfort knowing that as I watch Michael continue to suffer with his seizures, I have a heavenly Father who knows what it is like to have watched his son suffer, all without anesthesia or morphine.

God has used the church to minister to our family and shoulder some of the weight for us. We are grateful to many of you who have prayed for us, cared for us, and loved us. The following points are some of the ways the church has ministered to us and can help others in similar circumstances.

1. **Framework** - As I have pondered our circumstances with Michael, I have needed a framework to put the hard stuff of life into place. There needs to be sound theology that is biblically intact, to be able to think about the issues and cope with all of the facets that surround a situation like Michael's. I thank God for biblical teaching and preaching and for the encouragement of scripture memory, which has served to under-gird us for such a time as this.
2. **Pastoral Care** - Couples need the care and support of a pastor to assist them as they work through their grief. Couples are vulnerable in a number of ways. A couple's

faith may be jeopardized by false doctrines. Their belief system may collide head-on as they are confronted with the reality of a disabled child. The strain on the marriage relationship is tremendous as they work through all of the issues. One statistic I read stated that 85-90% of couples who have a special-needs child divorce.

3. **Small Groups** - After our original small group stopped meeting, it was the persistent invitation of Tom and Heather Lutz that persuaded Mark and me to drive across the metro to participate in their small group. Small groups have the unique opportunity to go beyond shallow Christian talk and go deeper in their commitment to one another and in their relationship with Christ. A small group cannot have a Michael in their midst and not ponder the deeper things of God.
4. **Good Friends** - We cannot be a good, deep friend to everyone, but certainly we can be a good friend to one, two, or three people. I am talking about the type of friend that you can call at 3 a.m. I thank God for Lyn, Mary Kaye, Ruth, and Heather. These are rock solid Christian women who cried with me, helped me, encouraged me, and listened to me. God is doing the battle, but my friends have held up my arms.
5. **Words of Blessing** - Be quick to listen and slow to give advice. One of the greatest gifts that you can give is one of a listening, caring ear. It may provide a way for a mom or dad to process what he or she is experiencing. There is very little that you can say to take away a parent’s pain. Unless the person has “been there,” or is in the trench with a parent, or may be in authority such as a physician or pastor, it will sound trite. People have been gracious with us showing much care with their words. Perhaps the sweetest words that were spoken to us were, “We love you guys.” “As

you ache to see Michael hurt, it hurts us to see you hurt." "We are with you for the long haul." "We pray for you all the time." These are words of encouragement that can be communicated verbally, by cards, or by emails.

6. **Actions of Blessing** - Michael was hospitalized five times over the last one and a half years. His longest stay was 17 days. During those periods of time, my biggest need was for childcare for my three older children. If our family could not come from out-of-state, some of our friends exhibited incredible flexibility doing whatever it took to accommodate our needs. There were many nights that I came home from the hospital to have my neighbor/friend resting on our couch with the house picked up, laundry folded, and the children tucked in bed. Other people have blessed us with meals and household help with the coordination efforts of Laura Wiering. Pam Olson has been involved in establishing a consistent team of people to come to our house for an evening to care for Michael and our other children. It allows Mark and me to have a break. These are incredible gifts of service and feel like balm on a sore. Other people have used their talents by making beautiful prayer cards to give to people. Let our minds run wild as we contemplate how we may serve one another with much love and mercy, doing the gift of service unto the Lord and not out of obligation or expectation. It allows me to accept it.
7. **Attitudes** - Let us examine our attitudes and beliefs about people with disabilities. Let us ask God that we not be conformed to the patterns of this world but ask God to renew our minds. If we look at Michael as our culture does, we will see him as a nonproductive drain on society. Instead, let us look upon him as a creation of God. Let us look at God's fingerprints on a being with an

eternal soul that is worth more than all of the possessions in the entire world. Let us ponder what the Great Potter has crafted and fashioned for His purposes and for His good pleasure. Let us see what He will reveal about Himself to us through people with disabilities. We are all pots that are broken and in desperate need of God's grace and mercy.

8. **Prayer** - The scripture passage that is on Michael's prayer card is taken from Isaiah 43:1-3. It states, "But now thus says the Lord, he who created you, O Jacob, he who formed you, O Israel: Fear not, for I have redeemed you: I have called you by name, you are mine. When you pass through the waters, I will be with you: and through the rivers, they shall not overwhelm you; when you walk through fire you shall not be burned, and the flame shall not consume you. For I am the Lord your God, the Holy One of Israel, your Savior." Let us pray this passage as well as other scriptures over people with special needs. Let us not just pray for physical healing, which God may or may not give, but as John Knight, the father of a special needs child has stated, let us pray for a greater need, one of spiritual healing for all of us.

May God give us eyes to see Him, even as His eyes range throughout the earth to strengthen those whose hearts are fully committed to Him. May God give us ears to hear the Shepherd's gentle voice even as His ears are open to our cries. Finally, may God give us the hearts to believe, even as He upholds us in His righteous right hand.

Standing on God's Promises,

Janet Lacher

Wife of Mark, Mother of Jonathon, David, Christina, and sweet, foxy Michael Lacher

you can get involved with DISABILITY *Ministry* OPPORTUNITIES

Will you prayerfully consider the following ministry opportunities at Bethlehem in response to this article? Call the church office at 612-338-7653 for more information on any of the following.

- **Prayer.** Join the Disability Prayer Group that meets monthly at Bethlehem.
- **Join an e-mail list of families that want to help.** You can find out how to help, submit & respond to prayer requests using this list. Call the church office to sign up.

- **As a Small Group, ‘adopt’ a family impacted by a disability**. Welcome a new member who is impacted by or dealing with a disability. In this way, you can grow in awareness and care by providing encouragement, prayer support and hands-on assistance.

- **Sign up for Nursery or Children’s Ministry.** Contact the nursery coordinator to apply to serve in our Nursery Ministry, or you can work one-on-one with a child at Bethlehem who has a disability by contacting the Children’s Ministry department for Children’s Sunday School Ministry.

Bethlehem Baptist Church
720 13th Avenue South
Minneapolis, Minnesota 55415
612.338.7653
www.bbcmpls.org