

Special Families

...A Casserole's Not Enough



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introduction

The title to this booklet and byline say who wrote it and what it is about; however, the origin of the title itself is a lesson in how to help parents. When I was at a meeting of parents with children with disabilities in my town, I was impressed by a couple that was eager to get their church involved in ministry to them and their son. My interest in their situation grew when I realized their son had childhood schizophrenia. I interviewed them for a special article. The answer to one of my questions made a lasting impression on me.

I asked, "What would you like to say to your church family about what you need...really need?".

Mother's response:

"My church friends bring food and help with physical things, and I am grateful; however, I would say to them 'sometimes a casserole is not enough'."

We hope the suggestions in this booklet will guide your ministry to meet the real needs of families dealing with disability. When you have put the concepts in this booklet into practice, you will be able to report a story like this one from Jackie's experience. To find out more about the story behind the title of this booklet, go to ccfh.org and click on "Blog" at the bottom of the page. Click on "September, 2007", then on "Childhood Schizophrenia: How A Congregation Can Help".

the Saunders family

About ten years ago, I was introduced to the Saunders family one Sunday morning between services. I met mom, dad, and three children. Davey, their youngest, was a cute, energetic child appearing incredibly active, with Down syndrome. Mom and dad shared they had some reservations about setting foot in yet another church. Asking why, I discovered at their previous church the pastor had told them not to come back...no need to...they had been absolved of all sin. Upon further questioning, I learned Davey had some behaviors the children's ministry leaders were unable or unwilling to support. On occasion, Davey was energetic/disruptive, sometimes non-compliant, and a runner. Because of lack of training or willingness to include him in children's ministry, mom and dad had no alternative but to bring him into worship service with them, during which Davey was at times unruly, loud, disruptive, and a flight risk. It was then the pastor, in a less-than-Christ-like way, shooed the Saunders out of the church.

Wounded and discouraged, they found themselves at the doorsteps of McLean Bible Church (MBC). Davey joined a class in Access Ministry with staff and volunteers trained and accustomed to behaviors like Davey's. Davey's sibs plugged into children's ministry and junior high, and mom and dad joined a community group. Mom joined a mid-week women's Bible study as well. After leaving MBC that first Sunday, Davey's older brother said, "Can we come back? That church treated us normally." The Saunders are a normal, all-American family: mom, dad, and three children, one of which has a disability.

Over and over again, I hear special families say, "We just want to be treated as normal and accepted for who we are." Isn't that what each of us wants? To be loved, valued, and appreciated? Loved unconditionally, as Jesus loves?

Fast forward ten years later. Mom and dad are still active in their community group. Davey is now in our young adult fellowship group, growing in his knowledge of God. Davey also participates in many of our young adult social outings (giving his parents respite) and is a member of our male mentoring bowling league, Striker Club. Davey's brother and sister have since both graduated from our youth group and are currently attending an outstanding Christian college. Both have served as volunteer leaders in our youth ministry and in Access.

The Saunders are a family fully integrated in the Body, and it all began with an intentional mindset to embrace and welcome Davey and his family. What would have happened had this family decided to give up on God and His people after their negative church experience? It could have been devastating. Instead, this family has thrived in all ways possible: spiritually, emotionally, and relationally with one another.



background for the writers' work in disability ministry

First, we want you to know about the reasons for our being in inclusive ministry. Jackie Mills-Fernald is the Director of Access Ministry with McLean Bible Church in Vienna, Virginia. Jim Pierson is retired founder and president of Christian Church Disability Ministry and associate professor of special education at Johnson University in Knoxville, Tennessee.

Jackie outlines her journey in disability ministry

I have no qualifications, except for the fact God qualifies the called, and for that I am very thankful. He often takes the least qualified to do His good works, so He would be glorified; such is the case here.

A little over 14 years ago, I was minding my own business one Sunday morning during a service at MBC, when the senior pastor made an announcement for a few more volunteers in the newly-launched disability ministry, Access. I'm not sure why I felt compelled to respond, as I had no disability experience or background. I showed up for my first service time, unsure of what to do as I watched in confusion the children who had no verbal ability and strange repetitive motions and fixations. I felt so out of place, so unequipped and unskilled, to have an impact. For some reason I kept returning, beginning to learn all I could about these precious children.

Fast forwarding 14 years, I am currently the Director of Access Ministry, which has grown from serving 4 families impacted by disabilities years ago to reaching out to over 500 families today, from 1 Sunday-morning program to over 25 programs at 2 campuses. Access is a ministry that doesn't just embrace individuals with disabilities but their entire families as well by providing spiritual, emotional, and physical supports. It is a ministry that goes well beyond Sunday mornings, offering the love of Christ daily to those families through a holistic approach, creating a church in which one never ages out of the church by providing alternatives to be fully integrated in the church life. We are "doing life" with families whose existences are complicated, full of challenges, divorce, financial stress, and such brokenness, often marginalized and devalued in our society, many times without knowing the hope of Jesus Christ.

Every day, I wake up fully aware of my inabilities and ineptness to be doing what I am doing, but I am fully aware of God's greatness and ability to do anything through me. I am blessed beyond measure serving alongside God, reaching out to those so often neglected and ignored in the community. Who better to love and show the love of Christ to than His people...a ministry of Jesus that cares for those in need. Daily, I serve Jesus by serving others.

Jim discusses how he started in disability ministry

My first real awareness of the needs of parents of children with disabilities started when I was the executive director of a regional children's rehabilitation center. What I noticed was when families were members of churches, there didn't seem to be any active programs to assist with their needs, especially the spiritual ones. As a result, I started researching what faith groups across the country were doing for people with disabilities and their families.

Quickly, two pieces of information emerged. First, to my surprise, something was being done. Even the early leaders of special education, Itard and Seguin, stressed the importance of religious education of their students with intellectual disabilities. Second, agencies serving people with disabilities were urged to support them and their families. I ordered the materials that were available, and treasure the copies in my collection of materials. Two of those agencies, United Cerebral Palsy and The Association for Retarded Children, had spiritual nurturing committees that encouraged spiritual development in the groups they served.

This interest developed into commitment to advocate for churches to open their hearts and services to people with disabilities and their families. During my time, I have made hundreds of speeches, lectures, and workshops on the topic. It has led to the writing of articles and books. "Exceptional Teaching" is a manual that assists Bible school teachers with the efforts to include students with disabilities. As a matter of fact, it was through one of my workshops at her church that my co-writer and I became compatriots.

I agree with Jackie that I am glad the Lord called me to this great ministry. Knowing people with disabilities have learned who Jesus is and their parents are receiving ministry is an unbelievable blessing. At my recent retirement dinner, I was deeply gratified by the number of families that attended to express their appreciation.

Working with parents over the years has convinced me they are one of the most committed, bravest groups among us. I have learned far more from them than they did from me. The one factor my early research and ensuing career taught me is Christian families want their children to be a part of their church family and embrace faith in the Lord Jesus.



advice after many years of service

The following information from us will provide some insight into how your church can assist the families you have in your inclusive ministry.

Jackie offers the following ideas

Managing family life in today's world is generally complex and taxing, let alone when a child has a disability; life becomes even more complicated and challenging in many regards. Demands increase, while time in which to complete them seems to decrease. Families often ask what they can do to survive. There is no easy answer, but certain practices and supports can be implemented to create family resiliency.

I believe the first thing is a commitment to care for oneself. Parents are so busy caring for their families, homes, and work that they neglect personal care, such as rest, respite, healthy lifestyle choices, and, of course, maintaining the spiritual disciplines of devotion time, reflection, and prayer, to be able to quiet out the noisy world and sit at Jesus' feet. Prayer is so important and frequently neglected when times get chaotic. It might mean helping hire a caregiver or mommy's helper for a few hours a week, so mom and dad can slip away together or perhaps individually. Encourage weekends away or short overnight trips. A rested, refreshed parent has more energy and patience. There is a reason airlines make the announcement to put on your mask before you help the person next to you—parents need to be at their optimal best.

When life is hard and caring for a child with disabilities seems consuming, it is easy for parents to shrink away, retreat, and resort to isolation. Help them resist the urge to do so. Instead, they should reach out by joining a small group in your church, a neighborhood play co-op, or a parent group. Surround parents with families and friends who can assist with simple tasks and errands, as well as with the care of their children. In the church, look for support through individuals and small groups willing to walk alongside families as prayer partners, friends, and helpers. Create a small village for them.

I have a few friends who continue to make sure I take time for myself, as well as look for ways they can assist my son Elijah, who has emotional disabilities. Because I am not good about asking for help, they just took it upon themselves to commit to being actively involved in my life. Raising a child with disabilities at times causes additional strain on husband-wife relationships and other family relationships, in addition to financial challenges. Out of pride, some parents do not ask for help until it is too late. Ask if they need help. Help them resist the urge to retreat, but to reach out to you instead.

Staying connected to community and church is essential to avoiding isolation and being cut off. Facilitate connections with organizations within the school system, adapted sports leagues, and professional associations to network, grow, and develop relationships, for the benefit of the parents as well as the children with disabilities. Because many children with disabilities have some social deficits or communication barriers, it is often more challenging to create and maintain friendships. Regularly, parents or other adults have to foster and facilitate such relationships by organizing activities or outings for their child with disabilities and other peers. Be intentional about including typical children in the mix to promote inclusive friendships and activities. Finding a church that cares not just for the child or individual with disability but the entire family is key to ministering to all.

“A family that prays together stays together” is such an important phrase for all families. Families impacted by disability need even more to be on their knees asking God for His presence, joy, and strength to make it through each day. Having extended family close by creates a solid support system; however, in so many transient areas, extended family members are hours away. The church can play a pivotal role when grandparents, aunts, and uncles are not handy, or in cases where family members have distanced themselves from the family in caring for the loved one with disabilities. Older persons from the church can become adopted grandparents, aunts, or uncles. Adopted family members can pitch in from caring for the child to helping around the house and running errands.

So what can we do as church leaders to care for and support our special families? Here are a few ideas:

- Connect them to one another (families traveling a similar journey).
- Connect them to community (small group or life group).
- Connect them to resources in the church (financial assistance, food and clothing ministries).
- Connect them to prayer warriors (who commit to praying for them daily).
- Create visitation teams to visit them at home or in the hospital.
- Provide meals or handyman assistance.
- Provide counseling or therapy referrals.
- Provide opportunities for respite or self-care for parents.
- Provide a church that welcomes all family members into the body with a commitment to love and care as Jesus would.

Jim offers some suggestions for church workers to share with families they serve

Working with families with children with disabilities for more than 40 years has been a wonderful experience. It has also been a great in-service training experience. Observing the families' attitudes toward their children and how they relate to the children, the people who work with them, and the rest of the family has led me to a strong belief that if the family creates a positive climate for the child with disability to develop, he or she will be a better-adjusted human being. So, how can a family create that environment? Study the following suggestions. Tell families to:

- 1. Love and nurture their children.** Hugs, a warm smile, and a kind word make for the attitude "I am loved and belong." Parents log a lot of time going to therapy, doctor's appointments, evaluations, and the like. Encourage them to use those times to affirm their children and to make the times happy ones together. The children will grow and develop surrounded by a real sense of loving and being a part of the family.
- 2. Talk to their children about his or her disability.** Down syndrome, Cerebral Palsy, and Autism happen to real people. To be told you are just like your peers is not fair. The child may wonder: "Why do they not have to go for speech therapy?", "Why are they not in special education?", "Why doesn't he wear braces?". If a child knows his diagnosis is a part of him but does not define who he is, he will be a healthier person.
- 3. Stress the positive traits in their children's personalities.** Tell them what beautiful smiles they have. Note their politeness. Encourage your friends who see your children often to express their positive traits. Such an approach will assist their children in leading a happier life and will influence people in their world. If they are in a safe, comfortable world with nice things to do, you are creating a wonderful world in which they can live.
- 4. Allow their children to do as much for themselves as they can.** Let them try. If they cannot, then assist by helping with an alternative to accomplish the task. Don't do for them what they can do for themselves. A wonderful lady who raised a very self-sufficient son with Cerebral Palsy jokes about the way she taught him to swim. She put a life jacket on him and put him in the lake. He is still a swimmer. He lives by himself and has adapted to his environment.
- 5. Advocate a spot for their children in the community.** Take advantage of what is available. Enroll them in the city's recreation department's summer program, go to Special Olympics, go to camp, and take them to church. The beauty of inclusion is we are rewarded by being a part of a group; and the more ways we are included, the better.

(The foregoing suggestions will help create a positive environment for their children to reach the peak of their God-given capacities. The following ideas will enrich that environment.)

- 6. Advise families they will need some extra help from time to time.** Take advantage of respite care. Whether it is informal through family and friends or formal through agencies, use it.
- 7. Encourage families to be open about their needs and the needs of their children.** Stress the importance of allowing their friends to help, not pulling away from friend support systems, and believing their friends can be trusted to do what is right for them.
- 8. Tell the families to find a person(s) who will walk with them in their journey of raising children with disabilities.** Having such a resource will add to their confidence and provide them with a sense of peace and a feeling of not being alone.
- 9. Remind them their family is a group.** Their children with disability is not the only member. Give each member attention. In the beginning, it might not be equal by time constraints, but it is a worthy goal. Spend special time with the children who do not have special needs.
- 10. Suggest befriending the people who work with their children.** It doesn't mean being intimate friends. The teachers, therapists, physicians, and caregivers who work with their children deserve your appreciation.

With the writers' general suggestions in hand, let's deal with some universal problems parents will face.

Observing the families' attitudes toward their children and how they relate to the children, the people who work with them, and the rest of the family has led me to a strong belief that if the family creates a positive climate for the child with disability to develop, he or she will be a better-adjusted human being.

finding respite care

Respite care sounds like a fancy word, but in truth it means

“from time to time, a family needs an extra pair of hands to prepare a meal, mow the yard, baby sit, listen, and otherwise be available.”

Studies about parents' most pressing needs will almost always reveal respite is number one.

Over and over again, special parents and families have shared the need to take time away from caring for their loved ones with disability 24 hours, 7 days a week. Respite care is often called the “gift of time”. It is a remedy for emotional, physical, and financial challenges many special families face. It is usually the most-requested support system. Respite programs/services provide short-term care of persons with disabilities, while giving the parent/caregiver “time off” for much-needed relief and rest.

The physical and emotional tolls on parents are significant. Many report chronic physical ailments, lack of energy, and sleep deprivation, while many experience anxiety/depression or stress-related illnesses. Respite can make the difference between a struggling family and a thriving one.

Creating a respite program(s) within the church can provide a much-needed service to families in the congregation as well as those in the community. Access Ministry of McLean Bible Church provides numerous models of respite care. Eighty percent of those who participate in programming is from the community and not from within the church. What a wonderful opportunity for outreach and to be the hands and feet of Christ outside the church walls. There are many different models of respite to consider. Ideally, start where you are. Launch a program that meets the immediate need, church vision, and budget.

Start small, dream big! Here are some program models to consider for your church and community.

1. **Home-Based Model** – Train up volunteers or teams of volunteers to provide respite care in families' homes.
2. **Site-Based Program** – Respite programs held at church or at a facility for multiple participants
3. **Parent Co-op** – Connect parents within church to create a caregiving network for one another.

4. **Camp/VBS model** – Create inclusion in existing church programs, so persons with disabilities are more readily able to participate (overnight or day program options).
5. **Respitivity Weekend** – Provide a weekend away for parent(s) with vouchers to local hotels and restaurants.
6. **Retreats/Couples' Getaways** – Sponsor special-parent getaways at church retreats (men's, women's, couples'), and provide care while gone.
7. **Respite Funding Pool** – Create a fund to help pay for respite care providers for families.

Access ministry offers a myriad of choices from site-based Friday-night and Saturday-day programs to overnight beach retreats, day-camp programs, and in-home care. We began with one program on Saturdays for six hours once a month, a service which has now grown to a menu of respite options.

Last year, MBC opened Jill's House, an overnight respite care facility with summer camp, school-break programming, and weekend respite options. For more information on Jill's House, please visit jillshouse.org.

All the services, outreach, and program ideas are wonderful to consider and implement; but the most important gift we can give is the gift of self, loving unconditionally and accepting our special families for who they are, celebrating their strengths and differences – not trying to change them but loving/embracing them just the way they are – as we acknowledge all were made perfect in His image.

For more information and resources on respite, please visit:

- MBC Access Ministry Blog: accessministryblog.com/
- Key Ministry: keyministry.org/

common concerns

people working with parents of children with disabilities need to be aware of a common concern: who will care for my child when I am not able to do so?

The following information isn't meant to make you an expert but to give you an understanding of the process.

In preparing for their child's future, there are two questions the family should answer. First, where will the money come from for his/her future care and needs? Second, where will he/she live?

First, what will be the source of the funding?

Tell families there are banks, financial planners, and lawyers to help them. There might be someone in your congregation who can guide them. Ask them if there are awards of government money available. Their plans should be in some legal document, either a will or a trust fund. The best advice is to start early with a plan for future funding for their child.

Second, who will provide care when you are gone?

"What will happen to my child, if something happens to me?" is a question that starts almost from the moment of diagnosis. Instead of the operative word "if," "when" would be a better choice. In all likelihood, someone else will be responsible for the care. Following are a few suggestions to help families think through the decision:

- **Learn the residential options available to their child.**
- **Deal with the cultural belief the family is putting away their child.** Many parents are haunted by the idea and feel guilty even to think about placement.
- **Consider it might be in their child's best interest to be in a place of his/her own when it comes time to leave the nest.** It is a normal cycle of life for a child to go to college, get married, get a job, or just move out of the nest. When a child with disability faces that time, it might be good for him to have a place of his own in the community or region. No matter where it is, the family can still be a part of his/her life.
- **Allow their child to develop his/her own community and circle of friends.** Many adults with cognitive disabilities have the same set of friends as their parents. They deserve their own world. A mother told me she could not watch another Charlie Brown movie with her daughter. When the daughter went to a place of her own, she relished making

cookies for her housemates and having the highest reading skills. Her new-found friends loved to watch Charlie Brown movies.

- **Guide the family's response to a frequent statement by other parents:** "We will wait until something happens to one of us." Make the family aware they will have to deal with two major upheavals without them: death and adjusting to a new living situation.
- **The family should communicate clearly to their child the reason they are seeking residential placement.** Tell the family the importance of stressing they are not getting rid of him/her, but to affirm their love, say how much he/she means to them, and explain they want him/her to continue to grow as a person.
- **Affirm with the family they can remain a part of their child's life, and they can be a part of the ups and downs.** It is the same as when a child without disability goes to college or gets married. As parents, they can continue to be an important, valuable part of his/her life.
- **The family should be proactive.** In a legal document, they should express their feelings about the care they want their child to receive, where it will be, and the person who will oversee it. Suggest writing a letter stating what they expect, and attach it to the document. It will clarify and enhance their wishes for their child's care, while keeping the family in charge of their child's care.

There is a wealth of information in print and online about preparing for a child's future, especially how he/she will be funded and where he/she will live when the parents can no longer provide. The best advice I gave was, "DO IT! Don't put it off." Write a letter expressing your feelings. Take it to an experienced lawyer, and get the process started as soon as you know your child's dependence on you is long term.

– Nathaniel's Hope (resource for life planning): nathanielshope.org/



working with the school system is another area with which parents need help

I am sure someone has done a study on how parents react to the school system during a Multidisciplinary Team Meeting. To somewhat quote the Wife of Bath's assessment of her husbands, "some of them were bad, and some of them were good." I have an idea parents' reactions to the school system would be "some are good, some are not good". My best piece of advice is to get an advocate to go with them to IEP meetings. Having support from someone who is on their side will make a difficult time easier. Some churches offer public school advocacy support as their inclusive ministry. It takes some training and some experience, but it makes a world of difference to the family. An often-asked question is "Can an outsider legally be there?". Yes; the parents can ask whomever they want to be present to help them plan for their child's future.

Many special families have faced challenges in working through school issues, from a teacher concern or classroom placement to other students. Many children with disabilities start in the public school system as early as two years old (with proper diagnoses) and can attend up to 21 years of age. Oftentimes, parents expend a great deal of time, energy, and resources attempting to get their children the education mandated by federal law; however, due to budget constraints, lack of skilled professionals, and overworked school staff, many services that should be available seldom are. As church leaders, we need to be aware of possible school concerns and stress, so we can properly interact with and pray for our special families. Be sensitive to children who are going through rough patches or transitional issues in school, as that could very well affect those children's behaviors in church programming.

If a child with disabilities is showing success in children's ministry, Awanas, or any other program, parents may request you attend the child's IEP meeting (Individual Education Plan) to share your observations or strategies for success. It might also be helpful for church leaders to get permission from parents to connect with teachers to learn what behavior plans or tactics work for them in the school system. After all, most children spend many more hours per week in a school environment than at church.

helping families with personal coping

Perhaps the best piece of advice I have offered people who struggle with how to cope with the presence of a child with a disability in their lives is to remind them that regardless of ability, everyone has a purpose for being on the planet. Knowing they are dealing with a person with

many words of appreciation at the time I said it; but over the years, they express their gratitude once they have proof it works.

keeping the family functioning in the life of the church

Many good Christian education programs have been started in churches because the parents of children with disabilities wanted their children to know Jesus, be a part of the fellowship of the Body of Christ, and perhaps embrace faith in our Lord. One of the purposes of this booklet is to encourage parents who are dealing with children with disabilities to come alongside parents who already do so and to develop ministries that will make a difference to them and their families. Using this approach will make others aware of the need and give parents the opportunity to work in another area of the church. When I asked one mother why she and her husband were bringing their daughter to our church, she responded, "I want to be in a church where I am not the only person concerned about our daughter's spiritual being." Providing a ministry to the child with disability frees the parents and siblings to find their places in other ministries within the church and to further their spiritual development.

making the family aware of the importance of community involvement

Special Olympics, Americans with Disabilities Act, IDEA, and mandatory education are just four elements that make us cognizant of the importance of people with disabilities being involved in the community. I have told parents, "Let your child experience life as much as his/her disability will allow." Encourage parents to take advantage of the opportunities in their communities, e.g. join the Scouts, learn to swim, get a job with a fast food restaurant, attend church, play soccer, etc.

A special family oftentimes pulls away from the community, and a real sense of isolation sets in. It tends to be easier to stay home than to be out at a restaurant, mall, or playground and risk having a child with disability melt down or exhibit some behaviors other people might not understand. Integrating persons with disabilities into the community helps teach the rest of us acceptance or awareness. So how can we encourage not just church involvement but community participation as well? As church leaders, we can assist in the following ways:

- Provide a buddy/caregiver to accompany families to community events.
- Stay abreast of events in the local community that are family friendly.
- Encourage community connections from which all can benefit.



giving information about strengthening the life of the family

Remind parents their child with disability is only one member of the family. Suggest they share their time with other siblings as equally as they can. Tell siblings not to internalize their feelings about their brother or sister, but to share them. Join a Sibshop. For extended families, encourage grandparents to be as involved with their grandchildren with disabilities as they are with the others. The gifts of love and acceptance without reservation will be a positive in the child's development.

Disability affects every member of the family. Often we realize the effect on the person with disability and his or her parents but stop short of looking at siblings and extended family.

Siblings (younger and older) are impacted by their special brothers or sisters. Typically at a very early age, they have been thrust into a caregiving role out of necessity. Time and again, they have had to defend their siblings as others made fun of, bullied, or teased them. Children with disabilities are four times more likely to be bullied than typical children. Often, siblings have missed out on social events, joining sports teams, or other things in which their peers are engaged because of the amount of time and level of care parents must provide their children with disabilities. It doesn't mean parents love their typical sibling any less; it's just the level of care required or the extra therapies and appointments for their special sibs that consume mom/dad's time. Because of lack of time or one-on-one with the typical child, they often act out to get attention. As churches that care, we can help by making sure children's ministry workers and youth leaders commit to spending time investing in the typical sib, who often is starved for attention.

We should also be aware of the mix of emotions a typical sib feels toward his/her sibling, ranging from anger to love, embarrassment to pride, or jealousy to blessing. Sibs need a place to share and process their emotions and to understand where God is in all of this. A church can help by creating a network to connect sibs to one another or facilitating some sibs-only social events or small groups. Being around other sibs with brothers/sisters with disabilities creates a sense of normalcy and connectedness. Check to see if there is a Sibshop in your community, and recommend it to siblings. If not, your church might consider starting one.

Grandparents often take on a significant caregiving role as they support their adult child in the care of their grandchild. Encourage grandparents to connect in church with community groups, a caregiver network, and to go to retreats and get away to be with God and balance with some "me time". For both parents and grandparents, it is important to encourage good health and healthy lifestyle choices, such as proper nutrition, exercise, prayer time, and spiritual disciplines.

read one family's story

Families of children with disabilities have amazing stories to share. Give them opportunities to do so. The following story is a good example.

Heather, Vance, and their four children, Jonathan, Sophia, Joseph, and Lily, are a special part of my life. My wife and I look forward to our times with them, especially at a local restaurant where we celebrate everything from Summer Begins to Back to School. Two of their children have serious vision problems, Joseph and Sophia. Joseph is an amazing young man. Over the years, especially at those meals at the restaurant, I have watched him become more and more independent. He no longer needs help with cutting his food or getting the straw through the plastic lid on his drink. It isn't, however, the major development. Spiritually, he has insights into life that some of us never know. The day Joe saw a rainbow illustrates it. His father Vance tells the story.

Joseph's rainbow

It has been a decade since my wife and I have accepted the reality that our son and daughter will never see a rainbow because of their deteriorating central vision. Often, we have tried to point them out. At times I have placed my arm next to their heads and help them pinpoint the exact location of the bright colors in the sky, only to hear the words, "I don't see it" and to see

the hint of disappointment on their faces. Being 14 years old, Joseph had also accepted this reality; but to use his words to his little sister, "We can be thankful we aren't totally blind."

One day, Joseph went fishing with his friend Levi. It was raining outside and my wife and I were watching a movie when we heard shouting at the front door, "Papa! Come quick!" On the front porch were two boys, soaking wet. Levi was holding up a huge largemouth bass, and Joseph was literally bouncing with joy. I said, "Joseph, you aren't excited are you?" He replied, "Yes, Dad, but not about the fish." He grabbed my arms with both hands. "Dad, I saw a rainbow!" Talking 90 miles an hour, he described to us how he had asked Levi repeatedly, "Really? That's it right there?". While pointing and tracing the arch in the sky with his finger, "It goes from there to there? Those lines right there are a rainbow?!". He explained how perfect it was: "The sky was gray on one side, and he could see lines in the clear sky on the other side.

With his Mother beginning to cry, he told us, "I've had dreams of seeing a rainbow, but I actually got to see a real one!" Heather wept.

Later that evening while Joseph was taking a shower, I went into the bathroom to get my shoes; and from behind the curtain came the words, "Dad, that was so awesome! I couldn't see the colors, but I could see the different shades of lines in the rainbow." I immediately felt a touch of disappointment realizing that he didn't see the color that most of us experience. The only words I could muster were, "Joseph, it is a blessing from God. It was your rainbow." My disappointment left when he replied, "It was a miracle, Dad."

How much clearer he sees through his eyes than I do through mine at times. I will never really grasp what a rainbow without color looks like or exactly what it looks like through Joseph's eyes; however, the joy our son had and the glory he gave to God for what he did see are superior to those of us that have witnessed the brilliant colors of a rainbow. I have never seen anyone who saw the real colors be more excited than our son was on that day.

Those who know Joseph and share their lives with him, those who know his daily struggles with his disability and the fortitude with which he meets them, and those who know his "story" will never again look at a rainbow as merely a reflection of the sun's rays on raindrops. Joseph's experience adds a testimony to God's goodness, promise, and hope as it did in Noah's day. Like a rainbow, Joseph's life, attitude, and compassion are so often a beautiful reflection of God's Son.



families speak for themselves

In planning this booklet, we decided to get ideas from nine families who deal with disability on a daily basis. A summary of the results follows. As you read their responses, you will learn a lot about the dynamics of family and disability.

Of the nine families, five have children with Autism; the other three have children with Down syndrome and one with Charge syndrome. There were 15 siblings in the 9 groups. In seven of the families, both parents were in the home. Half of the families had changed churches to give their children Christian education or spiritual formation. The children ranged in age from 7 to 27. One family has two children with a disability; the others only one.

When asked what they would like their ministers to know, four families were complimentary of the way their pastors and leadership understood their needs. A couple of families wanted their pastors to know how chaotic it is to raise a child with a disability, that enough money and a helpful spouse make a difference. One family suggested more respite, small-group support, making disability a priority, and the pastor should set an example. One family, whose church didn't have a disability ministry, wanted their leadership to know how people with disabilities are more like us than they are different.

The following is a list of the most valuable things the families' churches have given them:

- It has given my child a place to be loved, cared for, and taught the Word of God by an exceptional and caring staff.
- It has given us a place to worship.
- It has given our family an opportunity to come to church in a stress-free environment.
- It has allowed us to come to church together.
- It has provided a loving, accepting, and safe environment for our son and family to attend together.
- Our church is our family. The members rejoice with us in the best of times and support us in the lowest times.
- It has given our son adult buddies.
- It has provided acceptance. We feel very embraced.

Our third question asked for areas where their churches needed to offer more assistance.

- Three families wanted more attention to their other children and immediate family.
- One wanted more respite for families with children with more severe disabilities.
- One wanted their church to start a disability ministry.

- One family was blessed.
- Two left the question blank.
- One wanted more specific sibling support.

Because being supportive of siblings is an important part of a church's ministry, we asked the parents how their children handle their siblings with disability. There were only eight responses because one family has only one child. The other responses were as follows:

- Mostly with love—but with no respite help.
- She accepts him wholeheartedly and is a blessing to her brother.
- Overall she is caring, and gets upset when her sister doesn't play what she wants her to play.
- Fine.
- Most of the time they are loving, helpful, and understanding; at other times, uncomfortable and protective.
- Sometimes with compassion; sometimes with no empathy.
- She adores, protects, is gentle with, and demanding of her brother.
- His siblings are supportive and loving at times. Other times, however, they are typical of any siblings. They always give him special attention.

Following are reasons why children treat their siblings with disabilities well:

- She understands it takes her sister longer to do tasks.
- They know God created him, that he has purpose, and the family is here to help him fulfill that purpose.
- We see him as a blessing not a burden.
- We have not let the disability interfere with our family's full participation. We keep life as normal as possible. We see a blessing not a burden.
- We find dealing honestly and openly with the disability and not letting it interfere with our love for each other works for us.
- We see our son as an equal, and he is treated that way.
- Early on, we explained his sister's developmental delay was the cause of the behaviors he didn't understand, not his sister.

We asked the families for the scriptures that have been helpful to them in reacting to their children with disabilities.

- Psalm 139:12-15; James 1:17
- John 9
- Romans 5:3-5
- Philippians 4:13; Proverbs 3:5-6; II Corinthians 12:9; Isaiah 35:3-6; Isaiah 40:28-31; Isaiah 42:16; Isaiah 55:8-9; Psalm 139:7-6; Revelation 21:3-5; Isaiah 61:1-3
- Jeremiah 29:11 (three families)
- Don't worry about tomorrow. (Matthew 6:34)
- Isaiah 40:31
- Philippians 4:13; Romans 8:28

We asked our families to offer their best advice to parents who are new to disability. The responses are enriching.

- God is still good. God is in control, and He has a plan for your child's life. Despite our failings, He will see His plan come to fruition. We don't have all the answers. Just trust Him.
- Advocate for your child.
- Know God is holding you in His heart. I know it is difficult, but God is more interested in our character than our comfort. Use respite to strengthen the bonds between your family members. Enjoy your child with special needs.
- If you don't know Jesus, get to know Him. Quick! Network with other special-needs parents. Find good doctors.
- Get information from an organization that deals with the diagnosis. Find a support group. Keep a notebook, a section for each professional seeing your child. Because you need to be a team, maintain a good relationship with your spouse.
- Pray and follow God's leading. Educate yourself about the disability and the law. Love your child for who he/she is.
- Hold each other up when you feel like you have been socked in the gut. Know God has a plan. Live with boldness and confidence. Get help and advice from those who have walked a similar road.
- Your child is not a mistake. Enjoy serving in the wonderful world of disability to which your child has led you.
- Don't always believe everything the "experts" tell you. You are the expert on your child. Strengthen the relationships that uphold your family.
- Be in a community of faith. Prioritize your family's growth and development, and don't get bogged down with the issues of raising your child with special needs.



Families are often stunned at the public reaction to their children with disabilities; so, we asked our families how they handle it.

- Ignore the ignorant!
- Ignore them.
- Ignore them. Our child is friendly, which keeps stares to a minimum.
- It's hard in the beginning, but you develop a thick skin. I just think to myself my son's happiness and rights to enjoy public spaces are more important than my discomfort.
- Not well. I zone out and pretend no one is looking at us.
- When you offer a smile, you will either get one back, or they will stop staring.
- Smile, and say "hello." People with special needs are always on display. We have learned to accept it for what it is.
- It has been a process of maturing and learning how to respond. Our family often receives kind words and glances because our child is so cute and a social butterfly; however, we have had our share of negative moments. Something you just have to have about it is grace, and ignore them. Through prayer, we call on God to open their hearts and strengthen our resolve to shine His light into their lives for that brief moment.
- Humor and tenacity will help your child not to deal with shame that stems from the reactions of people who don't understand.

A long-standing need in families of children with disabilities is respite care. Our question to them was, “do you have regular respite care?”. The answers speak for themselves and should cause congregations to act on a real need.

- Only through the blessing of our church’s ministry.
- We have Medicaid Waiver, and grandparents live nearby.
- No.
- Yes, thanks to the church.
- Somewhat. He can stay with his siblings. The church program provides breaks.
- Yes; family members provide it for us.
- Nothing formal. We rely on friends and family members.
- No.
- Not really.

We were interested in learning whether our families worked in their churches’ disability ministries. Hoping the number would be low. It was.

- Three said they didn’t.
- Three said they did.
- Two help as needed.
- One is working on getting a ministry started in their church.

Our final question was to assess how our family members were ministering in the church apart from the disability ministry.

- Seven families were active in other areas of the congregation.
- One left a blank.
- One didn’t have a volunteer position in the church.



conclusion

What happens when congregations realize a casserole is not enough and commit to not just meeting physical needs but spiritual ones as well? Lives are transformed by the redeeming love of God through His Son, Jesus.

reflect on what happened to Dustin

Every year, Access Ministry runs a four-week summer day camp program designed for children 5-15 years old with disabilities and their siblings. Many of the families that participate are not members of MBC and may/may not share the same theological beliefs as MBC members. They choose to enroll in the camp despite differences in religious views because the camp's reputation is fabulous, complete with one-on-one staffing, enriching camp activities, and exciting field trips. We do not hide the fact or shy away from our Christian views and beliefs, and all are welcome, regardless.

Meet Dustin, a young camper from a few years back. Dustin was an 11-year-old boy on the Autism Spectrum, raised in an Orthodox-Jewish home. His mother asked before camp started if he could be opted out of Bible curriculum time. We gently told her no, and assured her there would be no Bible thumping. During the second week of camp, the curriculum's theme focused on Christmas in July and Jesus' birth. As you can well imagine, Dustin had plenty of questions to which he demanded answers. Dustin is incredibly bright and has good communication skills. After a couple of days, he requested more information and a Bible. By the end of the week, he felt he had enough information to pray and give his life to Christ. A few staffers prayed with him, and he accepted Jesus as his savior. He went home that night; and during dinner, he told his parents. Awkward moment: Jewish parents now hearing from their son he has converted to Christianity. He shared his Bible and the truths he had learned from it. Mom and dad began sharing with our staff the positive changes they were seeing in their son—everything from attitude to obedience to joy.

Since the time Dustin accepted Christ, his mother is now a believer, as is his older sister, and they are all still praying dad into the Kingdom. One small child learning about Jesus in a special-needs camp impacts the Kingdom!

As we continue to include individuals in church services, programming, and opportunities to fully connect, we impact special families in ways we can't even imagine or anticipate. Begin by being intentional to include all; then commit to sharing and doing life with these special families by supporting, loving, nurturing, and raising them up as leaders, just as Jesus would have us do. Meet the need; then teach His Truth in word and deed.



Access