Making Sense of Autism

By Pat Verbal

We often hear from pastors who say, “Parents bring children with autism to our church, and we don’t know what to do with them!” We also hear from parents who say, “In society, we face fear and isolation because our children have autism. But when we go to church and feel rejected, it hurts even more.” In this chapter, you’ll meet families who are bravely navigating the complicated world of autism. Their frustrations and tender joys may surprise you, as well as their total dependence on God. You’ll discover that families affected by autism don’t always want to be on the receiving end. They have a lot to offer. In fact, God tells us that our churches will never be complete without them.

—Joni Eareckson Tada

In the early 1970s, I attended a church in St. Louis, where I volunteered in the children’s ministry. Our director called me one Saturday to discuss a new family who would be visiting our Sunday service. She didn’t know much about their eight-year-old son, John, except that he couldn’t be in class with other children. I quickly offered to stay with John in a separate room. As I gathered Bible storybooks, music tapes and art supplies, I prayed for God’s help in teaching John about Jesus. But instead, John taught me about autism.
Evolution of Our Awareness of Mental Health

_Dallas Morning News_, February 15, 2010

The bible of mental illness, the *Diagnostic and Statistical Manual of Mental Disorders*, is being revised for a 2013 release. It will play a significant role in shaping policies in schools, workplaces and courts, and has huge implications for the insurance industry. For the first time, it may include individuals with autism spectrum disorders, which would have not been widely recognized years ago.¹

The Autism Society estimates that in 10 years, the annual cost of autism could be as high as $200 to $400 billion.²

Back then no one knew about “autism,” or at least we didn’t use the term. People considered John “retarded,” and his parents never said much. All I knew was that this beautiful boy with the big brown eyes continuously rocked back and forth, sometimes banging his head on the wall. He never gave me eye contact, and he spent hours twisting pieces of string around his fingers. He didn’t like to be touched and never spoke a word, yet God gave me a special love for John. He liked me, too, although I can’t remember how I knew that. I just did.

Once, on John’s birthday, I took a cupcake to his home. The house was neat, but in the corner of the dining room stood a tall cage-type enclosure made of wooden slats with a lock on the door. John’s mom explained how they sometimes used it for John’s own safety. Even as a young person, I understood that John’s parents
loved him, because kids like John were usually institutionalized. But the thought of that cage always haunted me.

Today, autism is out of the closet and making headlines. According to The Autism Society, 1 child in every 91 born in the U.S. will have some form of autism. The figure is 1 in every 150 in the general population. This developmental disability affects a person’s communication and social interaction. It is characterized by repetitive behaviors, restricted interests, resistance to change, and unusual responses to sensory experiences. Parents of children with autism grapple with early intervention programs. Doctors, teachers and therapists team up to support families coping with this ever-evolving diagnosis. Yet, autism is not a debilitating disorder. These children will likely one day be 60-year-olds with autism.

As Christians, we can’t close our eyes to children with autism. We are called to have the same compassion Jesus had when He pulled the little children onto His lap and blessed them (see Matt. 19:13-15). Because we sometimes fail to see children with special needs through God’s eyes, we can slip into the disciples’ role of rebuking children. They just don’t fit in—their needs and actions are different.

Making sense of autism is a daunting task. It’s so multifaceted that it is considered a spectrum disorder. I thought of this when I read Frances Chan’s book Crazy Love, in which he described God’s innumerable designs in our universe. Chan points out that God didn’t have to make hundreds of different kinds of bananas, but He did. He didn’t have to put 3,000 different species of trees within one square mile in the Amazon jungle, but He did. God created a caterpillar’s head with 228
separate muscles, and crafty spiders that can produce three different kinds of silk at a speed of 60 feet per hour. He even gave you and me goose bumps that cause the hair follicles on the back of our neck to trap body heat to keep us warmer when we’re cold.⁴

Wow! God’s designs are beyond our wildest imagination. The world’s intricate beauty silences our finite thoughts . . . until we look deeper only to discover that all the “good” seems to exist alongside of the “evil” on our planet. For example, why are there so many disabilities, such as Asperger’s Syndrome, Pervasive Developmental Disorders, and Rett Syndrome, which are all on the autism spectrum? Why do children experience uncontrollable behaviors, painful sensory issues, meltdowns and seizures? In other words, why autism?

Maybe you know of families whose lives are completely overwhelmed by the challenges of autism. You want to embrace them as brothers and sisters in Christ, but you simply don’t know how to help. Or, you may be misinformed due to some common myths associated with a diagnosis of autism. Think about a time when you have felt misunderstood. Maybe a friend took your comment the wrong way or a coworker misquoted you in a meeting. Perhaps a Christian friend told you to consider it all joy when you face trials such as these because they produce perseverance (see Jas. 1:2-3). Now, imagine having a child with a disability that is so ambiguous that people actually point fingers at you—the parent!

**Myths About Autism**

Shrouded in mystery, autism makes parents of autistic children feel as if 1 Corinthians 13:12 was written just for them: “Now we see
but a poor reflection as in a mirror . . . . Now I know in part; then I shall know fully.” Someday, God’s bigger plan will be revealed to all of us. For now, your friendship can comfort these families. And the first step is to dispel the myths about this disorder.

Myth 1: We Know the Causes and Cures for Autism
When children are diagnosed with any disorder, parents typically ask, “How did my child get this?” and “What will make him well?” For children with autism, these questions have yet to be answered. “We absolutely don’t know the cause of autism,” says Dr. Jeff McNair, Director of the Masters of Arts in Disability Studies at California Baptist University. “Autism is a spectrum disorder, involving a myriad of different disorders. There are therapies that can help, but no one therapy works across the board.”

A simple shopping trip used to result in a meltdown for nine-year-old Caleb Bundy. He would fall to the floor, screaming and slapping his honey-blond head. Caleb’s senses became overwhelmed in busy, noisy stores. However, after four months of therapies such as social scripting and behavior modification, Caleb was able to enjoy shopping with his mom and brother. Like Caleb, Alessandro Barrero has autism, but he communicates his feelings with a picture exchange system, an alternative way of communicating without speech. And thanks to sensory integration therapy, Alessandro and his dad can enjoy playing in the park on sunny afternoons.

However, there is no one-size-fits-all approach. Even children with autism who are in the same family can have very different needs and interests. For example, consider the Anderson brothers, Joel (18) and Jared (21). Joel is nonverbal and has difficulty
walking. He is hypersensitive and likes to listen to soft music. Jared
is hyposensitive and wants his music loud. Joel’s therapy includes
a gluten-free diet, but diet changes didn’t seem to help Jared. “You
name it, we’ve tried it!” says their mother. Unfortunately, that
statement is all too common among families coping with autism,
and many times they feel as if they’re grasping at straws.

Myth 2: All People with Autism Have Mental Retardation

Have you ever heard someone you care about called “stupid” or
“retarded”? Has anyone ever made you feel that way?

Our culture often portrays children and adults with autism as
stupid or mentally deficient, because they have difficulty receiv-
ing and processing information. Parents like Rosie Barrero, whose
son Alessandro has autism, take offense. “We’re tired of hearing
our children called ‘retarded.’ While friends and teachers don’t use
the word, it shows in their actions.” Once, when Alessandro’s abil-
ities were questioned, the Barreros took a laptop to his school to
demonstrate that he could read flash cards. Afterward, the school
changed Alessandro’s education program. “It’s the saddest, most
horrific feeling in your heart when someone doesn’t believe in
your child,” says Mrs. Barrero. She wants people to know that chil-
dren with autism are complete on the inside, and it’s a tragedy to
underestimate a child’s potential. “I think that is what God meant
in Proverbs 22:6, when He said train up a child in the way he
should go,” she says. “God’s design for each of us is perfect.”

An avid gardener knows that it’s not about the hours spent
weeding or watering—it’s the thrill of watching a bud burst forth,
or smelling a vine-ripened tomato. It’s about an appreciation for
potential beauty and flavor. But with autism it can be difficult
to recognize the hidden treasures in the minds and hearts of these children.

In 1 Corinthians 1:26-27, Paul describes true wisdom: “Brothers, think of what you were when you were called. Not many of you were wise by human standards; not many were influential; not many were of noble birth. But God chose the foolish things of the world to shame the wise; God chose the weak things of the world to shame the strong.”

Steve Bundy understands how someone can look at his son Caleb and think he is mentally retarded. “Sometimes a person will have a dual diagnosis; but to assume across the board that someone with autism also has mental retardation is just incorrect. It is a very different way of processing information and learning.” Research has shown that a child or adult with autism can have a very high IQ, or even be a genius.

People with autism can learn. The question is, can we teach them? We can if we take extra time to break down tasks into bite-sized pieces, learn to use visuals and lots of repetition. We can if we stay flexible and refuse to give up.

Myth 3: All People with Autism Behave the Same
While there are similarities in learning styles and behavior patterns among individuals with autism, there is no way to determine how a person with autism will behave every time and in every situation. For example, Caleb must use a message board to ask for more grapes; but Jacob, who speaks clearly, often gets confused about what he wants to eat. When his mom presses him for an answer, Jacob would rather play than decide. Joel is on the other end of the autism spectrum and loves to talk about his art.
He began speech therapy to correct his “echolalia” (involuntary, repetitious sounds or words) at the age of two. Now, at age 15, Joel speaks to thousands of people through a foundation that demonstrates that people with autism can do many things.

Dr. Diane Cullinane, who is a Developmental Pediatrician specializing in children with autism, makes this observation: “These children have their own special interests and ways of responding to the world in terms of sound, movement—what they like to do and how they communicate. Their development is unique because their families are unique, as are the relationships within their families.”

Clinical psychologist Ben Zequeira-Russell agrees, “I find that people on the autism spectrum have more of a diverse representation of capacities than those who are considered typical in their development.”

Myth 4: Autism Is Caused by Lack of Discipline and Poor Parenting

Most parents feel inadequate at one time or another. But for parents of children with autism, this feeling is reinforced by hurtful remarks from people who are simply ignorant about autism. As Christians, we must ask ourselves why it is so tempting to judge parents by their children’s actions. Rosie Barrero confesses that she once vowed never to have an unruly child. That was long before she experienced her son’s first meltdown at a Target store.

The myth that autism is the result of poor parenting originated with Leo Connor, who defined autism in the 1940s. Dr. Ben Zequeira-Russell disagrees with Connor, suggesting that many parents respond to their child’s diagnosis by increasing their attention to parenting. Dr. McNair agrees: “Parenting is not a contributing factor to autism. Parents can be the most loving, af-
fectionate, wonderful parents in the world, and their child will still develop autism.”

Sandi Anderson has grieved over rude comments about her sons, who both have autism. “Some whisper that it’s the sins of the parents,” says Mrs. Anderson. “One person asked why I would give blood, because of how my sons are—I’ve been stunned that people can be so mean.” These comments hurt, but they can also cause parents to draw closer to God. They did for Mrs. Anderson: “Finally, the Lord calmed my heart, because He knows when I give the best that I can give each day. So, now when someone says something that stings, I know that tomorrow it will be a great story.”

Autism requires that families ask for help, and there is no better place to go for understanding than the church. Right? It’s where we practice being kind and compassionate to one another (see Eph. 4:32). We don’t speak against our brothers or judge them (see Jas. 4:11). Alessandro sums up the care we must show families, when he says, “Be gentle!” So the next time you see a child throwing a temper tantrum in a public place, pray for that child and for his or her parent. Learn where there are parent support groups meeting in your community that you might recommend if the opportunity arises.

Now that we’ve dispelled the myths that can block our path to understanding autism, let’s consider the truths that unite us in the Body of Christ. In Proverbs 24:3-4, we read, “By wisdom a house is built, and through understanding it is established; through knowledge its rooms are filled with rare and beautiful treasures.” Let’s consider how churches can become more welcoming when we treasure families affected by autism.
Treasured Truths About Autism

Christian friends can make a huge difference in the lives of children and adults with autism. Romans 12:5 says that “in Christ we who are many form one body, and each member belongs to all the others.” For many of us this kind of “belonging” will require a major shift in our thinking, but the transformation can bring glory to God and a fresh maturity to the church. For example, if we think that individuals with autism can’t understand spiritual truths, we’ll miss the joy of teaching them about God. If we think they only want to be cared for, we won’t experience the blessings that their love and service can bring into our own lives.

Sarah Stup, 24, is out to change the way we think about people with developmental disabilities. She declined typical employment options to pursue her passion for writing, and she has received several advocacy awards. Sarah is nonverbal and can’t control her ritualistic behaviors. She has support that allows her to offer the world some amazing insights into autism. Here is an excerpt from her book *Are Your Eyes Listening?*

- I am inside.
- The words are there; the voice is not.
- It is lonely and sad not to talk.
- We who are silent have our value.
- Being autistic is a battle that stays.
- Your world hurts me.
- Sounds pay me visits after I leave them.
- I need autism to breathe.
- Autism is awful, but I am not awful.
- I act dumb, but am smart. Please be my friend.
We can’t be friends when you hate autism.

• Be an explorer who finds treasures beyond the strangeness. ⁹

Sarah wants us to know that autism is part of a shield that she and others like her need. Without it, she wouldn’t be who she is. You can read more of her work at www.SarahStup.com. Sarah is planting seeds of truth about this disorder, and they are blossoming.

Truth 1: Autism Separates Families from the Church

Have you ever felt painfully alone in a crowded room? If so, you’ve had a glimpse into the world of parents whose children have autism. These parents walk through our church doors every week, assuming their fellow worshipers don’t understand their needs . . . and they’re right! As a pastor of Christian Education for over 20 years, I’ve seen these families hurt emotionally and spiritually by our ignorance. We fail to notice that they can’t always do what other families do. I have also watched autism’s power drive a deep wedge between spouses, siblings, extended family and friends.

Autism is hard on parents who sometimes battle loneliness—even in their own homes. “What’s really lonely is spending the day alone with Caleb,” admits his mom, Melissa Bundy. “People don’t understand how sad it is to not know what your child is thinking or to be unable to share your day with him.” Parents, especially single parents who face these difficulties alone, can also feel guilty over not giving equal time to active siblings.

Dr. Scott Daniels, with whom I’ve served in two churches, has grown to appreciate the special needs ministry at his church.
“These families are limited in the places they can go within the community to find connection due to the challenges they face,” says Dr. Daniels. “As our church truly becomes a genuine community, we’re capable of bringing encouragement and healing. But I wonder what the prospects are for couples who don’t have that unique community.”

Surely these families are crying out as David once did in Psalm 142:4: “Look to my right and see; no one is concerned for me. I have no refuge; no one cares for my life.” Julie Keith, director of In His Image at Dr. Daniels’ church, is also concerned: “I know of churches that have not responded to these precious families as Christ would, and those families are no longer in church.”

How can we get these families connected within our faith communities? Church consultant Barbara Newman recommends using glue. Yes, you read that correctly—G.L.U.E.! This acronym stands for Giving, Loving, Understanding and Encouraging. Newman worked with the CLC Network to create the G.L.U.E. Teams concept. She holds seminars for churches, training them to do “ministry with” rather than “ministry to” those with disabilities. These techniques provide practical ideas on giving support to families where, when and how it’s needed to allow them to fully participate in the life of the church.

Truth 2: Autism Creates Fears that Christian Friends Can Ease

Remember dreaming about celebrating your sixteenth birthday, driving your first car and receiving your first real paycheck? Your parents may have worried about how you would handle new responsibilities, but they were also excited for you. The
worry and anxiety for parents of children with autism is magnified by the reality that their children may never even be capable of experiencing the most basic pursuits and privileges of life.

Brandi Urlaub is concerned for her son, Jacob. “My biggest fear is that it might be hard to find somebody who will really be there for Jacob,” she says. “I worry about his safety and wellbeing if I’m unable to take care of him.” Bill and Mika Buffington wonder if their son, Billy, will ever have a career and family. “I don’t know who my son will be at age 25,” says Mr. Buffington. “I’m dealing with today, but I don’t know what tomorrow is going to bring.”

None of us can know what the future holds for our children, and these fears can only be alleviated by truly embracing Christ’s message of hope and peace. That’s why God planned for us to grow and share in a community of fellow believers. “I try to remind myself that I have no control over the future,” says Mrs. Buffington. “That’s something that I continually pray about. I take all fearful thoughts captive and put them before God. He is the one who already has the blueprint.” Mrs. Buffington’s faith sustains her when she gets discouraged. She’s learned to trust in God’s sovereignty and lean on her church family.

Truth 3: People with Autism Can Know and Serve God

Some churches do an admirable job caring for children with autism but are unclear on what to teach. How much can they understand about faith in Jesus Christ? Since God created each of us with a unique purpose, we dare not underestimate the work of the Holy Spirit. “It’s our spirit that comes to know God,” says Julie Keith. “Our students with autism grasp God’s love for them and how to share it with others. As I’ve watched them grow, I see that
His spirit is much more powerful than the human mind.” Steve Bundy also sees this in his son: “Caleb needs a relationship with God as much as anyone else. It may look very different because he doesn’t process information in the same way typical children do, but nevertheless, he needs spiritual instruction.”

I’ve enjoyed spending time with Caleb, but the first time I came to his home, he kept his distance. He watched me when he thought I wasn’t looking. He didn’t respond to my questions or want to give me a hug when I left. But I wasn’t discouraged. I knew that in time, if I let Caleb lead the way, I could show him God’s love by being his friend. On a recent visit, we had a breakthrough. I entered his house with a gift box that I set on the floor. His curiosity drew him to the package, and soon we were both sitting on the floor touching the bright-colored paper. Then he lost interest and wandered into his room, waiting to see if I would follow. I did and took the chance to sing softly with the rhythm instruments from his toy box. At dinner, Caleb watched me and smiled when I included him in the conversation. He played with the wooden cars from the gift box. After his bath, Caleb snuggled next to me on the couch, putting my arm around his shoulder. As the family played a word game, he joined in with single-word answers, surprising all of us. Caleb’s actions showed me that he felt loved and accepted, which was an answer to my prayers.

People with autism desire relationship. They need to see the evidence of Christ in our lives. Without that, how can they accept the gospel? “No one from the church has ever offered to help us,” says Brandi Urlaub. “If I went to the church and asked for help, they might find someone available. But we haven’t been going to church much because it’s just too hard.”
Families like these live in neighborhoods near your church. The Great Commission in Matthew 28:19-20 sends us out to make disciples of all people, teaching them to obey Christ’s commands. “We misunderstand Christ’s mandate when we allow the government to take the church’s role,” says Dr. Daniels. “We lose so much of who we are as the Body of Christ. We’re people called to be salt and light in the world.” While social services can help, they can never lead a child to Christ. However, when we go in Jesus’ name, we can introduce a whole family to our Lord and Savior.

Truth 4: Autism Can Strengthen Faith Communities

We have seen the importance of embracing families affected by autism, but there is also a lot we can learn from them. “These families teach us how to love other people,” says Dr. Jeff McNair, who teaches adults with disabilities at his church. “If someone comes to me with poor social skills, and I reject him, I’ve sinned—he didn’t. So, if the Lord brings people into my life who are socially incompetent to teach me, then that is another benefit.” When we act with the mind of Christ, we have a tremendous opportunity to grow alongside these families. At whatever age a parent’s child is diagnosed with autism, our response should be: “We don’t care what your child’s disability is; there’s a place for you here.” This goes beyond just providing childcare so families can worship, to helping them fully participate in our fellowship.

While leading a training seminar at University United Methodist Church in San Antonio, Texas, I visited their Helping Hands Ministry. This ministry is a group of young adults
with disabilities who serve the needs of the church. Emily has hypersensitive autism and keeps to herself, but she likes to quietly straighten up and restock the sanctuary racks with envelopes, pens, hymnals and Bibles. Some days she fills children’s worship tote bags with puzzles, worksheets and crayons. Another day she might prepare craft projects for preschoolers. But Emily doesn’t like to serve at the Thursday senior adult luncheons, because she prefers to eat lunch by herself. Although Emily doesn’t give eye contact or speak much, she knows she is needed at her church and everyone is glad she is there.

My friend Molly Kantz enjoys talking about the things her younger brother has taught her. In her book My Brother Willson, she describes him as an active nine-year-old who loves computer games, Bugs Bunny and karaoke! But he doesn’t like being told no, or hair dryers, macaroni and cheese, or sounds he cannot control. Since Willson’s kind of autism makes him hyposensitive, he likes touching everything, jumping on her and playing under the covers. She writes, “I am much tougher because of Willson. . . . I have amazed my friends with my patience. . . . I think God put autistic kids on earth to make us wish for heaven where everything will be perfect. . . . Even though I wouldn’t choose for Willson to have autism, it has been a good influence on me and my family. I love my brother, even if he does have autism!”

A special-needs ministry can touch the whole congregation. “As we see that God has well-intentioned plans for these children, it is transformational to us,” says Dr. Daniels. “We have become a better people because we have this kind of ministry—living, laughing, and struggling together to become the Body of Christ. Without those challenges, we are just a group with like interests.”
Why Autism?

In the beginning of this chapter, I asked, “Why autism?” Let me suggest that God encourages our questions. Yet at the same time, He asks us to walk by faith. I can personally tell you that I feel God’s presence when I spend time with families affected by autism, and they are changing me. But I’ll turn to wiser people than me who have attempted to answer the question.

As a young child, Eric Hendrickson’s autism diagnosis included extremely sensitive hearing; sounds were painful for him. However, what appeared to be a negative trait became an area of strength as Eric learned to cope with sounds. His keen ear led him to pursue language studies in college. In his high school valedictorian speech, Eric addressed the “why” question: “I was born with a serious handicap. . . . I have often been tempted to ask, ‘Why can’t I be more like everyone else?’ This is when I must consciously remind myself of the truth that my life is not a mistake, God designed me JUST THE WAY I AM, and he has a purpose for me even in the things about me that are different. Perhaps especially in the things about me that are different. I have to make a conscious choice to believe what God’s Word says is true about me, rather than believing what the world says about my value and importance.”

Joni Eareckson Tada says, “God made it clear that following Him would mean real hardship. Life is supposed to be difficult. More than that, it has been granted to us to suffer. Granted? Like a gift or a privilege? And what does ‘for Him’ mean? Problems are built into the Christian life for a privileged purpose. If we’re to follow Jesus, we have to follow Him to Calvary. That’s something God wants us to understand the moment we come to
Christ. God also wants us to realize it’s a privilege to follow His Son this way. To follow Christ to the cross is to suffer for Him.”

Pastor Francis Chan concludes, “Whatever God’s reasons for such diversity, creativity, and sophistication in the universe, on earth, and in our own bodies, the point of it all is His glory. God’s art speaks of Himself, reflecting who He is and what He is like.”

Autism is one of the mysteries of faith. God chooses to use those who we perceive as “weak and less wise” to stretch us, mature us and teach us about His love.

Thank You, God, for parents who never give up on their children. Open my mind and heart to see children with autism as You see them. Use me to strengthen these families in my neighborhood and church. Don’t let me miss Your love shining through these precious children. Amen.

STUDY QUESTIONS

1. Why is it so tempting to judge parents by their children’s behaviors? What does this say about human nature?

2. How would you react if there were no cure for a disorder that you or your loved one was facing?

3. If you had a child with autism, how might your family’s weekly activities change?

4. If you spent the day with a child with autism, what might be the most challenging thing for you?
5. How would you respond to someone who says that caring for children with autism is the job of the government, not the Church?

6. What qualities did you see in the parents in the chapter that you want to emulate in your own life?

7. Have your perceptions about individuals with autism changed after reading this chapter? In what ways?

8. What would practical support from your church look like for families affected by autism?