Locked in Their Own World

Autism can destroy families. But some parents of autistic children are using Christian faith to help others face this misunderstood condition.

Mary dresses her son Nic in his favorite Batman pajamas and cowboy boots after changing his diaper. Dark circles under her eyes reveal the numerous times she rose to feed and comfort him during the night.

Nic doesn’t speak, and Mary wonders when he’ll say his first word. Until then, she’ll continue to watch his eyes to determine his needs, as she’s done since Nic was born.

Her own eyes catch sight of her appearance in the mirror. Her only consolation for the haggard reflection she sees is that, thanks to Nic, she won’t be going out in public anytime soon. What would other people think if they saw us? Mary wonders.

Friends and family were more sympathetic when Nic was a baby, but now he is 7.

Welcome to the world of autism spectrum disorder (ASD), a developmental disability that was almost unheard of only one generation ago but today affects more than 1 million people in the United States, according to the Autism Coalition.

Nic’s parents, like many others who have autistic children, navigate mostly alone through their son’s erratic behavior, social withdrawal and uncontrollable tantrums caused by the slightest change in his routine. Getting help for Nic is an allconsuming task that has drained their mental and physical energy, their financial resources, and their faith.

Despite advances in awareness, diagnosis and treatment, ASD remains a lifelong condition—and the autistic person is not the only one affected. For parents and families, an autism diagnosis is devastating.

Death of a Dream

Classic autism was first identified as a neurological disorder 50 years ago. Experts now define it as a "spectrum disorder" diagnosed by a person's degree of a wide range of tendencies and behaviors.

Though its cause remains unknown and often is hotly debated, it is believed that genetics and rapid brain growth during early childhood are significant factors.

Although no two people with ASD are exactly alike in their symptoms, they do share certain social, communication, motor and sensory problems that affect their behavior in predictable ways. Some are highly functioning with intellect intact. Others may be mentally retarded or mute, or have serious language delays.

The grief process that parents of autistic children experience—denial, anger, guilt, depression and finally acceptance—is as real as if their child actually had died. That child's life will no longer follow the course they had imagined, and they must find a way to let go of their dreams for him or her.

Rebecca Wagner Sytsema was close to delivering her second child when the realization that her first son, Nicholas, had

autism began to sink in. Sytsema, daughter of Global Harvest Ministries President C. Peter Wagner and executive director of Children of Destiny ministry, recalls experiencing a period of devastation. “You have to reset all your hopes and dreams and thoughts,” she says.

Diagnosis was also the low point for Jerry and Sheryl York, founders of Gate of Destiny Discipleship Center in Ingleside, Texas. The Yorks have two autistic daughters, Erika and Destinee. The couple were within days of the birth of their third child when they learned their second daughter had mild autism.

“I began to cry, wondering why this happened to us twice,” Sheryl recalls. “I wondered what was wrong with us.”

Joni Parsley, wife of pastor Rod Parsley of World Harvest Church in Columbus, Ohio, agrees that she hit rock-bottom when their son, Austin, was diagnosed at age 3 with Asperger’s syndrome, a high-functioning form of autism.

“The first thing they tell you is that there’s no hope, no cure, no treatment,” she says. “And it was very difficult to hear that and process it and get your fight back.”

Getting your fight back is a task most Christian parents of ASD children credit to their faith in God.

“Reading the statistics can really drain your faith,” says Jack Sytsema, Rebecca’s husband and vice president of finance for International Child Resource Development Center in Melbourne, Florida. “But then you’ve got to make sense of your faith and say: OK, that might be reality, but what God says

always triumphs over statistics.”

An Overwhelming Burden

Even with God’s help, the day-to-day grind is unbearable for some. “We sometimes felt it was way too much for us,” York says. “Sitters didn’t last, services were not offered, and to be honest I doubted I was going to keep my sanity.”

The mental planning required to keep an autistic child in a much-needed routine is a big challenge.

“If you miss it, you get a meltdown,” Parsley points out. “It can be mentally exhausting.”

Nic’s mother, Mary Sharp—who is a family physician in East Lansing, Michigan, and author of The Gift of Autism—says the stress autism places on family life affects siblings, too.

“I felt guilty about what I’d done to the big kids’ lives,” she writes in her book. “I felt bad about the embarrassment they suffered in public with Nic’s outbursts. I felt guilty about all the relaxing summer vacations they never had, the spontaneous trips to the ice cream store we never made, the uninterrupted snuggling bedtimes that never were, and the energetic, enthusiastic mother they never knew.”

She adds that before Nic came along she had illusions of perfection as a mother. “One of the ways that Nic has profoundly altered our life is that I feel that I’ve been able to give over a whole lot to … God’s will, God’s work, God’s business—not mine,” she told Charisma.

The Yorks have been moved to a similar place of trust in God.

“We have really had to seek the Lord for our own healing of the legalistic mind-set that we were somehow in sin because this happened to our family,” Sheryl York says. “In praying and searching the Word for the answers, we found that God was in our lives in an awesome way and had a plan and purpose for our family.”

Parsley admits that ASD has placed limitations on her family but says she has learned to live one day at a time rather than trying to envision the big picture.

“If you look at five years from now and wonder if you’ll still be dealing with this, it’s overwhelming,” she explains. “So we just say: ‘Today, this is what’s before us. And sufficient for today are the cares of today.'”

Parsley keeps her prayers for Austin simple, too.

“My prayer is that he is happy and he’s healthy and he knows that he’s loved and that he’s uniquely gifted of God,” she says. “I don’t want him ‘healed’ in a way that would take that away. I’m embracing it. I don’t believe God gave him autism, but I know God gave us Austin.”

Although Parsley believes special-needs kids are “miracles in progress,” she wants people in the church to embrace them as more than that.

“If they’re always looking at this ‘poor child,’ then they

don’t realize often what a tremendous gift they are,” she points out. “They can teach through the struggles they have and the courage they have.”

A Blind Spot for the Church

According to some parents, limiting autistic children as people to be pitied is only part of the church’s problem.

“I have heard countless people say they no longer go to church because it is too difficult with their kids,” says York. She notes that churches update their facilities to accommodate people with physical disabilities but don’t do the same for those with mental and emotional disabilities.

“Jerry and I both feel that the world is getting better for disability, but the church stands blind to the needs because of its beliefs,” says York, explaining that she thinks Christians who believe in supernatural healing are uncomfortable around a person who has not been healed yet.

The Sytsemas can relate. “We have so many horror stories from parents,” Jack says. “It just breaks your heart when they go to church and they’re not welcomed because of their child. I think some of these churches … think it’s contagious.”

“Or they think it’s demonic,” Rebecca adds.

The Sytsemas receive e-mails from parents who have been rejected by churches after prayers for healing or deliverance did not produce instant changes. They want to clear up misconceptions about autism and deliverance.

“We’ve had some of the best deliverance ministers in the world lay hands on Nicholas, and it wasn’t a demon.” Rebecca states adamantly. “Because they do things like flap their hands and rock, it can look very demonic. But it isn’t. It’s just their way of feeling their bodies.

“There are ways that the enemy does take advantage of these children and there are times when deliverance is necessary,” she says. “But I don’t believe there’s necessarily a spirit of autism you can just cast out.”

The Parsleys also know parents who have been told their lack of faith or hidden sin was to blame for the autism.

“That’s just criminal. That’s spiritual ignorance and immaturity,” Joni Parsley notes. “If you want to meet the giants of the faith, meet the parents. They’re not behind a pulpit. They’re fighting for their kids’ lives—for their next breath sometimes—for them to eat something, for them to go to sleep. They’re fighting for the miraculous every day.”

Sharp believes that Christians who view healing or deliverance as a way to make the autistic more like everybody else are missing the point.

“I don’t think we’re supposed to change people to fit some external definition of what is ‘normal,'” she says. “I think, ultimately, we’re judged by our ability to love. And when you are given a situation like this, that’s what gets tested—to simply love this individual for who they are, not who they aren’t.”

Forging Support

So how can the church community take off its blinders and begin to accept and support special-needs families?

The Sytsemas say there are no clear-cut answers because people with autistic disorders have such varied symptoms. After an unsuccessful attempt at attending a large church with Nicholas, they now attend a small Lutheran church where the pastor has uniquely reached out to them by offering to pay someone to watch Nicholas while the couple attend church services.

“We were just shocked, you know, that he was willing to pay someone to do one-on-one with Nicholas so that we could both go to church together,” Jack says.

Sharp, an Episcopalian, says she has tried many different ways to include Nic in worship services but that the experience is too uncomfortable for him. What has been successful, however, is a relationship that has developed between her curate, Father Phil, and Nic. The two meet once a week.

“Phil takes him into the sanctuary and they’ve been talking with God and it’s just so gentle and slow,” Sharp says. “Nic has a concept of God now.”

Sharp believes that offering families a respite—similar to baby-sitting—is one way Christians can build bridges. “Saying, ‘I will come over to your house and you tell me the five things I need to do to keep your child comfortable and feeling safe while you two go away for two hours,’ is profoundly meaningful for a family,” she explains.

In addition, Sharp suggests that other ways the Christian community could help autistic families is by integrating special-education techniques into Christian classes or worship services and by holding a separate church service for special-needs people and their families.

York says her family's prayer is that "one day we will have a church where even the disabled will be welcomed, loved and cared for." Children are not second-class citizens, she points out, even if they are disabled.

"These precious little ones were also created in that secret place, and God foreknew and predestined them as well," says York, referring to Psalm 139:13-16. The Yorks' autistic daughters join them in ministry, laying hands on people and praying for them.

"We know God is the healer. … We will believe until the end for our girls' healing," she adds.

"There is hope," Jack Sytsema says. "The reality is, there is no cure. But that's not the truth of God. It doesn't matter what medical science says. It really matters what God has told you."

Defending the Weak

Prayer leaders Jack and Rebecca Sytsema launched a unique ministry to support parents of autistic children.

Every child has a destiny, and God has a plan for every

child.”

These words are more than a motto for Jack and Rebecca Sytsema, ordained ministers who have been involved in international prayer ministry for the last 10 years. After their son Nicholas was diagnosed with autism spectrum disorder (ASD) in January 2001, the Sytsemas started a Web site called Children of Destiny () as a way to network families of children with the disorder.

The idea for the site—which includes daily prayers, weekly messages and an Autism Strategic Prayer Network—sprang from the realization that ASD families suffer spiritually and emotionally from isolation.

“We started finding out that most of these people couldn’t go to church,” Rebecca says. “It became real clear that the parents and families were very broken and had no one to minister to them.”

Visitors to the site repeatedly asked the Sytsemas how they prayed for Nicholas. “We heard that over and over and over again,” Jack says. As a result the couple wrote some prayers for the parents and later posted them on their Internet site.

“It exploded!” Rebecca exclaims. “We had over a thousand people sign up in the first month alone.” They pray for every request that comes in, but nothing excites them more than teaching families how they can pray for their own kids.

“What we usually do is find a Scripture and base a prayer on that Scripture,” Jack says. “Some weeks we may really target healing, but then some weeks we may target helping them to do

well in school and blessing all the teachers.”

They also focus prayer on finances and the parents’ relationship with each other, both of which are greatly strained when caring for a child with the disorder.

When the Sytsemas get discouraged, they read from a journal they have compiled that contains prophetic words spoken about Nicholas. The couple say they have had “the privilege of being surrounded by prophets” who have given prophecies to their son.

Rebecca encourages other parents to do the same with their children, even if they haven’t received prophecies about them. She suggests each ASD couple compile a journal of Scripture verses they perceive as being directly related to God’s plan for their child, and then pray those passages over their son or daughter.

The Sytsemas understand that overcoming discouragement is a primary need for ASD families. They recently shared these words of encouragement on their Web site: “We take hope in the words of Jesus to His disciples; our greatest rejoicing should come knowing that our names are written in heaven (see Luke 10:20). When we remember this truth, it gives us strength to continue our prayers for Nicholas, and continue waiting on the Lord.”

A Shoulder to Cry On

With an autistic child of her own, Ohio minister Joni Parsley started a ministry for kids with special needs.

The vision for Bethany Place, named for the biblical place of refuge and comfort, was birthed in Joni Parsley’s heart shortly after her son, Austin, was diagnosed with Asperger’s syndrome at age 3.

Joni, wife of Rod Parsley, pastor of World Harvest Church in Columbus, Ohio, remembers bringing her son to the church and watching the service on a TV monitor.

“One day the Lord spoke to me and said, ‘You need to make this possible for other families,'” she says.

Parsley now teaches other churches how to start special-needs programs. She says her goal is to make it possible for parents to come to church and receive encouragement and support.

“Sometimes it’s just a shoulder to cry on,” she says.

That shoulder often belongs to Sandi Jordan, co-director of Bethany Place.

“I’ve been where they are, and I know what they feel” Jordan, who spent years caring for an invalid husband, told Charisma. She considers it a privilege to take calls from frazzled parents at all hours, often crying with them before offering prayer and encouragement from God’s Word.

Families are also provided with meal deliveries and hospital visitation.

“I often volunteer to take the parents out for dinner, or to

sit with the child so they can get away from the hospital for a while," explains Jordan, who sometimes stays the night in the hospital to offer respite to parents.

The volunteer staff minister to as many as 17 special-needs individuals and their caregivers, and Parsley credits the Bethany Buddies program for making everything run smoothly. Children who volunteer to be Bethany Buddies learn to minister and interact comfortably with special-needs people.

"Many handicapped children are still cognitively normal, and they understand that nobody wants to play with them," Parsley says. "So when a kid from Bethany Place comes up to them and wants to play with them or wants to paint their nails, it's just special."

Debi Peterson, who co-directs Bethany Place, says churchgoers often ignore special-needs children because they don't know how to approach them.

"I want to raise up a generation who will not be uncomfortable around people with special needs and who will understand how to connect with them," she says.

The vision doesn't stop there. Parsley admits excitedly that she would love to build an all-inclusive therapy center with everything under one roof.

"You negotiate a maze to just get your child educated and helped, to find out what they need and what's available. And the church should be more than a spiritual resource, it should be a resource for this type of information."

For more information, go to

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