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See Me, See

ABSTRACT: *Autism Spectrum Disorder (ASD) is on the rise, with one in 68 children diagnosed with ASD. Families of children with ASD speak of being* othered*–feeling like outsiders in social situations. Because of ASD prevalence, all nurses need to understand current research, causes, symptoms, diagnosis, treatment, and how to offer effective support. Nurses within the faith community, especially parish/faith community nurses, can play a significant role in creating a welcoming and supportive environment for children with ASD and their families.*

KEY WORDS: *Asperger syndrome, Autism Spectrum Disorder, DSM-5, faith community, nursing, patient education*

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*Gabriel's name is used with permission.

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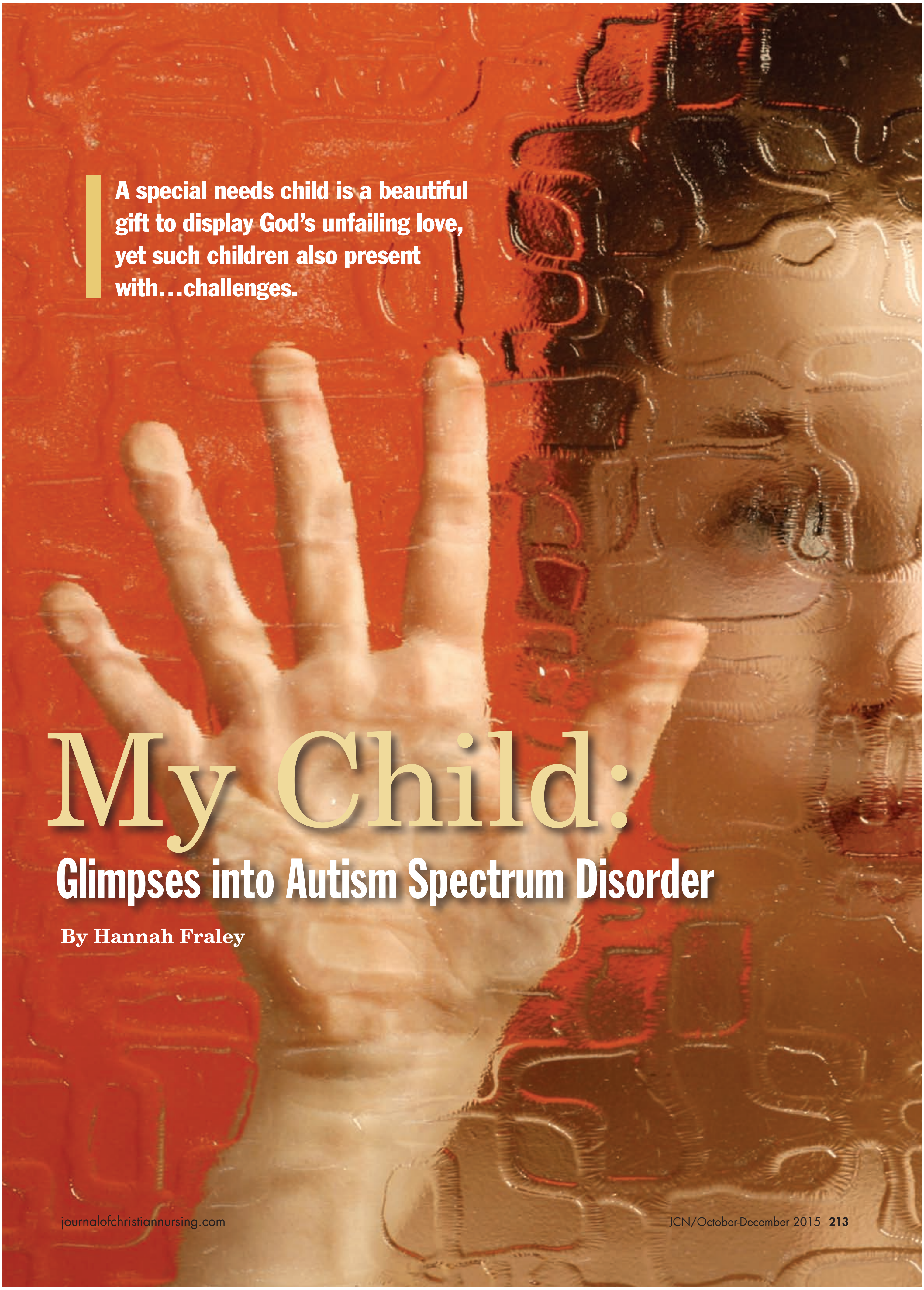
A special needs child is a beautiful gift to display God's unfailing love, yet such children also present with unique and highly complex challenges. As a mother of an 8-year-old boy with Autism Spectrum Disorder (ASD), I know the joy-filled life full of blessings, and the life of heart-wrenching lonely hours of worry and anguish. It is the hours of deep despair and of great joy that inspire me to relay the experience of raising a child with ASD. My goal is to educate about ASD and shed light on how nurses, who encounter children with ASD and their families, can have an impact on understanding and caring for their unique needs.

UNDERSTANDING ASD

Autism Spectrum Disorder is considered a neurodevelopmental disorder, mainly characterized by communication and social interaction deficiencies, restrictive and repetitive behavior patterns, sensory integration dysfunction and dysregulation, and limited and narrow interests, along with other characteristics and physical symptoms (American Psychiatric Association [APA], 2015). ASD affects tens of millions of people worldwide and over two million in the United States (Autism Speaks, 2015). According to the Centers for Disease Control and Prevention's (CDC) *Autism and Developmental Disabilities Monitoring Network* (ADDMN), autism has shown a 10-fold increase in the past 40 years and continues to be on the rise, with an estimated one in 68 children diagnosed per year in the United States (CDC, 2015). It is not clear if ASD is on the rise, or if there is an increase in detection or in environmental influences. ASD is more common in boys (one in every 42 boys), particularly Caucasians, than in girls (one in every 189 girls) (Autism Speaks, 2015; CDC). It is not known why boys are more susceptible.

ASD is characterized as a *spectrum* disorder, meaning it presents as a wide variation of disabilities; no one person on the spectrum is exactly like another. Until release of the Fifth Edition Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013), ASD was diagnosed as one of four disorders: autism disorder, Asperger syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). Now one term, Autism Spectrum Disorder, reflects a condition that has a range of severity of symptoms in two core domains: 1) deficits in social communication and social interaction; and 2) restricted repetitive behaviors, interests, and activities (RRBs). Both domains must be present for a diagnosis of ASD. If social deficits exist without RRBs, a diagnosis of Social Communication Disorder (SCD) is made. A severity level of One, Two, or Three indicates increasing severity of symptoms. For example, an identification of High Functioning Autism is noted under DSM-5 as "ASD Severity Level One." Additionally, under DSM-5, individuals with ASD must show symptoms from



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My Child:

Glimpses into Autism Spectrum Disorder

By Hannah Fraley

early childhood, even if the symptoms are not recognized until later on (Coury, 2013). A goal of the DSM-5 classification is that a diagnosis be used to make recommendations for interventions, which is a goal of the DSM-5 classification, rather than pin a specific identification on a child (Coury).

DIAGNOSIS AND TREATMENT

The clinical picture of ASDs varies from severe cognitive, functional limitations and limited ability to interact with people, to those on the high end of the spectrum with gifted, genius-level intelligence (APA, 2015; Moore, 2002). About 40% of those with ASD have an intellectual disability, classified as an Intelligence Quotient (IQ) less than 70; 25% of these individuals are nonverbal but can learn to communicate in other ways. Of the remaining 60% with ASD, many have an above-average IQ, with special gifting in visual, music, and academic skills (Autism Speaks, 2015). Depending on severity of symptoms and treatment, many children with ASD grow up to lead productive lives.

Early diagnosis is important because earlier treatment can make a difference in development and response to ASD. ASD can be diagnosed as early as 18 to 24 months of age; however, children as early as 8 to 12 months may exhibit signs, such as no back-and-forth babbling or gestures between parent and child (smiling, waving bye-bye, etc.). By 16 months, children with ASD may not be speaking meaningful words or speaking at all. By 24 months, they may not engage in social games, are not speaking meaningful two-word phrases (other than mimicking), and prefer to play alone. It is common for these children to have difficulty regulating their emotions; they have verbal and physical outbursts, particularly in new or frustrating situations. Some engage in self-injury behavior, such as head banging. Persons with ASD often are unable to appropriately express themselves or read the emotions of others and speak in monotones (Autism Speaks, 2015).

Diagnosis of ASD is made by analysis of a child's development and behaviors. A team of a pediatrician, child psychologist, occupational therapist, and speech and language pathologist typically assess and make a diagnosis of ASD. Often, those with ASD have other physiological problems such as seizures, gastrointestinal (GI) problems, and sleep disturbances. Genetic testing and evaluation of comorbidities may be recommended as part of the evaluation.

Both behavioral and pharmacologic interventions are used to treat ASD. Pharmacological treatment of physical concerns helps with behavioral issues such as attentiveness. Early intensive, comprehensive behavioral intervention involves trained therapists working with the child and family in controlled settings and/or in the home. Different models have proven to be successful, such as Applied Behavioral Analysis and the Early Start Denver Model. In order for a treatment program to be successful, it must involve 25 or more hours a week of structured therapy, use highly-trained therapists, address core areas impacted by ASD (social skills, language, etc.), provide interaction with peers, actively engage parents and the family, and respect family beliefs and values (Autism Speaks, 2015).

WHAT CAUSES ASD?

As a poorly understood behavioral disorder, researchers are fervently searching for causes of ASD. ASD is thought to begin in early neural development *in utero,* due to genetic and environmental influences. A small number of genetic mutations have been found to cause ASD, whereas around 100 more may play a role in ASD. For example, a gene that instructs the making of the protein *delta-catenin*, which plays a crucial role in normal brain development, was recently found to be mutated in girls with severe ASD (Turner et al., 2015). Researchers believe this gene may play a significant role in all individuals with ASD.

In the presence of a genetic predisposition, *environmental stressors* such as maternal illness during pregnancy (infection, gestational diabetes mellitus) or increasing parental age, increase the risk for ASD. In a multinational study of over 5.5 million children, increasing parental age in both parents, and increasing gaps between the ages of mother and father, were associated with increased risk for ASD (Sandin et al., 2015).

In research examining maternal characteristics during pregnancy, preexisting Type 2 maternal diabetes and taking diabetic medications during pregnancy were not associated with ASD in offspring. However, onset of gestational diabetes mellitus (GDM) prior to 26 weeks gestation was associated with a subsequent diagnosis of ASD (Xiang et al., 2015). Increasing evidence supports that taking prenatal vitamins before and during pregnancy, especially folic acid in doses of at least 600 mcg daily, may decrease the risk for ASD (Autism Speaks, 2015).

Although the existence of ASD is higher in children conceived using assisted reproductive technology (ART), the association between ASD and ART is thought to be related to adverse prenatal and perinatal outcomes and multiple births, rather than ART itself (Fountain et al., 2015). ASD is associated with difficult births, where oxygen is decreased to the baby's brain. C-sections are not associated with ASD; however, underlying problems that lead to C-section may share an association (Autism Speaks). Children born preterm, even later and moderately preterm (32–36 weeks gestation), also are at higher risk for ASD (Guy et al., 2015). However, it is not known if it is issues related to preterm birth, or the early birth alone, that are associated with ASD.

Although popular belief persists that the measles-mumps-rubella (MMR) vaccine may cause ASD, no link between the MMR vaccine and ASD has been found. In a recent study of 95,727 children with older siblings, receiving the series of MMR vaccines was not associated with increased risk of ASD, even if the younger children were at higher risk because an older sibling had been diagnosed with ASD (Jain et al., 2015).

HELPING CHILDREN & FAMILIES

Given the growing numbers of children with ASD, parents are justifiably concerned about their children developing ASD, especially in light

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of few answers following diagnosis. Teaching parents the early signs and symptoms of ASD and administering the Modified Checklist for Autism in Toddlers, Revised (Autism Speaks, 2015), can identify children needing further evaluation.

In a multicultural study of families experiencing the diagnosis of ASD in a child, Lobar (2014) found that families progress through certain actions: seeking diagnosis, engaging in routines to control behavior, finding therapies (types of therapies), finding school accommodations, educating others, rising to challenges, and finding the role of spiritual and religious belief. Worldview and family perceptions were critical to how the families proceeded in taking action for their child. Spiritual beliefs and practices such as prayer offered important support, especially in Hispanic families.

While attempting to move through the grief process associated with the diagnosis of ASD, parents face many other challenges and often lack much-needed social support. Especially concerning is the fact that children with special needs and their families frequently experience the concept of *othering*; there is us…and then there is them. They feel marginalized, on the outskirts looking in, wanting to be let in and accepted, yet without the tools and support to navigate their experience. In a recent qualitative study, Harper, Taylor Dyches, Harper, Olsen Roper, and South (2013) reported that both mothers and fathers parenting children on the autism spectrum experience elevated stress levels, with common feelings of exhaustion due to caregiver burnout, as well as chronic grief and worry about the future for their child. Parental fatigue contributes to ineffective coping and parenting of the child (Seymour, Wood, Giallo, & Jellett, 2013). Harper et al. further note the lack of external support, particularly to support the marriage of the father and mother. Divorce rates are high among parents with a child with ASD (Karst & Van Hecke, 2012). Siblings of children with ASD can be left feeling as if they are on the sidelines. One 10-year-old elder brother I met described his life with a sibling with ASD as feeling "invisible."

Ekas, Whitman, and Shivers (2009) discussed a strikingly concerning finding among mothers of children with ASD, highlighting that spirituality in and of itself brings comfort and a way for mothers to cope, yet taking part in religious activities brought perceived negative emotional experiences. What does this feedback mean for the faith community as a whole, and how can Christian parish and community health nurses intervene in the lives of these children and their families? In order to frame the pressing need for intervention, a case study highlights an experience of one young mother, her boy with ASD, and a nurse who stepped out of her comfort zone.

A MOTHER AND HER SON

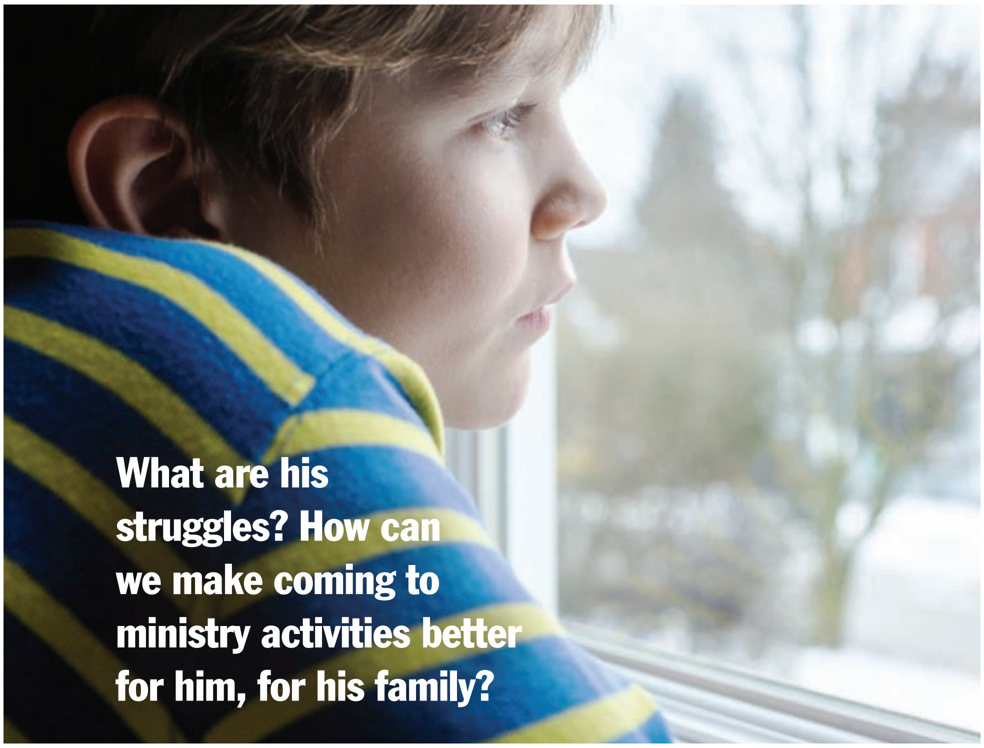
God introduced me to a special family at my church, a family who wore their struggle and pain on their faces while attending church activities. When I first really *saw* the family, it was the mother I was drawn to, as she sat alone, watching her young son struggling through choir practice, tears streaming down her face. I had observed the boy bolting from his mother as she calmly followed him, or hiding underneath a table with his hands covering his ears, appearing to be in pain, not understood by others. At times, he would try to kick his mother, shouting, "I hate you!" as she struggled to carry his growing body. Other times, I watched as she gently knelt at his level, reminding him of her love for him, of expected behavior, drawing him to her and embracing him, while his body melted into hers, hearing him telling his mother, "I love you , Mommy." Today the young boy was singing– what a beautiful voice, clearly he was musically gifted. He stood aloof from his peers, and at times made repeated hand movements across his hair, as if something was bothering him.

The boy with soft, friendly, blue eyes quickly glanced at me, his gaze fleeting and quickly distracted. At first he appeared just like any other 6-year-old boy, bouncing and wiggling. As a nurse, this child perplexed me. I wondered what his struggles were and how could we make coming to ministry activities better for him, for his family? How could we reach him; how could we reach out to his parents?

Sliding into the pew next to his mother, I gently put my hand on her shoulder. I said, "We are here for you; we try to understand even when it seems we do not." Her tears turned to sobs as she shared that she did not feel like we, the faith community, understood. "It's painful to come here; I go home feeling bad…. Everyone stares at my son, stares at me with accusatory glances, looks at my husband like he is not doing his job as a father, as a leader…making me feel I'm not parenting my son right. People think he is a bad, defiant, and disruptive boy." As she released her feelings with me, I also learned Gabriel* is a 6-year-old boy struggling with ASD Severity Level One, also known as High Functioning Autism or Asperger syndrome. Named after the biblical angel Gabriel, his name means "strong man of God."

Living with ASD makes it hard for Gabriel to cope with others and large settings. Part of Gabriel's disability includes sensory overload, including auditory sensitivity and difficulty processing environmental inputs, such as bright lighting, touch, smell, sudden movements, sounds, which all appear chaotic to him. Watching him brush his hair back and forth with his hand, I learned one of his coping mechanisms is to make repetitive hand movements. Gabriel also experiences dysregulation, where he struggles to maintain control of himself, his emotions, his body movements, and unintentional vocalizations.

This mother educated me about how hard the struggle is for Gabriel; our world is confusing to him. He has difficulty understanding the nuances of conversation and social interactions, as well as struggles to read the emotions of others and understand how his behavior affects others. Like one who speaks a foreign language, Gabriel needs a social and linguistic interpretor, often referred to as a social navigator (Moore, 2002), to help him understand verbal and nonverbal messages. In certain environments, Gabriel is overwhelmed by anxiety, leading him to display behaviors and emotions due to his confusion of his surroundings and difficulty with trying to understand his environment and those in it.



What are his struggles? How can we make coming to ministry activities better for him, for his family?

SEE ME, *SEE* MY SON

After our long conversation, I asked Gabriel's mother what we, as a faith community, could do to help, and what I, as a nurse in our congregation, could do. Readily she answered, "*See* me, and *see* my son." This response slammed my spirit. As a fellow Christ-follower and as a nurse, I saw the urgency of need for ministry and education in churches, and how the role of the faith community nurse can be pivotal in intervening with families struggling to raise children diagnosed with ASD. I was left pondering the question: *Do we see them?* Do we see God's special children and their family members in our midst? Are we aware of the great need to intervene and actively express love and care for these special people who want to be let in and not be *othered*?

As nurses in the community and at our churches, with intentionality, we *can see* the complex needs of these special kids and their families. We *can* begin to provide outreach, ministry, and acceptance. A first step is to ask: "Are they accepted and welcomed into our communities, sanctuaries, and Sunday school classes?" Unfortunately many families with a child on the spectrum, like me, describe a common theme of feeling judged by fellow parishioners,chronically feeling alone and isolated, *othered*. The church should, and can, be a safe haven for children with disabilities and their families. The church can offer acceptance and support, as well as compassion, empathy, mercy, and a nonjudgmental approach. Yet, many poorly understand ASD, which can result in parishioners and church leaders not knowing how to approach children with ASD or how to support the families.

A child with ASD physiologically cannot help his behaviors, which makes it painful for parents in the Christian community, as it mistakenly appears that: 1) the child is disobedient, and 2) the father and mother are not parenting well. It appears this child is not submitting to parental authority, often with behavioral outbursts, tantrums, lashing out at parents and others, when, in fact, the child is feeling overwhelmed. This misunderstanding leads to further isolation, lack of acceptance, and marginalization.

WHAT HAPPENED TO GABRIEL AND HIS FAMILY?

Several months of difficulty led this family to seek a new faith community, starting first with inquiring how the potential church includes special needs populations, particularly within children's ministries. Gabriel lives in the northeastern United States, in a rural town. His mother contacted nearly every church that professed a like-minded belief statement about God and the Bible, and then contacted the children's ministry directors. One director spoke about their special needs ministry and their robust inclusion model. She enthusiastically requested to meet Gabriel. Within days, Gabriel and his family met the director at a local park. Apprehensive at first, Gabriel clung to his mother. Mrs. Betty (not her real name) warmly stooped to his level, introduced herself to Gabriel, and extended a bag of healthy goodies and interesting items. The ice was broken. Gabriel's face lit up in excitement, not only excitement, but his body relaxed.

Gabriel has blossomed in this special children's ministry. Prior to starting Sunday school, Mrs. Betty sat with Gabriel's father and mother, learning about Gabriel and his unique needs, as well as what needed to be in place for him to successfully access all activities. It was decided that Gabriel would have a one-on-one volunteer, who would help him navigate the classroom, reinforce the concepts taught, and monitor when he might need a sensory break in the form of walks around the campus. Gabriel has come to love these walks with his one-to-one social navigator. She has not only sacrificed her time to help him but has connected with Gabriel; a mutual blessing has blossomed out of their relationship. Gabriel's mother at first struggled with letting go, with trusting the faith community again, afraid of potentially feeling the pain and rejection, as well as afraid her son would be *othered*. Mom hung close by, keeping a watchful eye. Yet, with time, the hurt and pain began to peel away, and she allowed God to heal her broken heart and bring her back into a faith family.

I wondered what was different at this church. What are they doing? Maybe others can model their program and improve their ministries to children. Mrs. Betty met with me to share her story of the special needs ministry within her congregation:

> *When I first became the Children's Ministry Director about ten years ago, we had a unique little boy attending our church who had cognitive disabilities, but his disabilities were hidden and not obvious. Sunday school teachers in his class kept quitting. I felt God nudging me that this just will not do…we have to be inclusive of all children. I contacted* Joni and Friends International Disability Resource Center *(2015), a well-known special needs organization. A consultant came out to our church, observed our program, and made recommendations on how we could improve to meet the needs of children with special needs. One of the major recommendations was to institute a parent meeting and questionnaire, specifically inquiring about potential special needs of children and to understand each child individually.* Joni and Friends *also recommended that we institute a one-to-one volunteer program for children who needed extra support within our children's ministry activities. We also regularly deliver special needs education class series for adults, in order to bring awareness and understanding among our congregation. We are not perfect, but since we have worked to improve our programs, God has transformed our church atmosphere as a whole. All children are made special and are loved by God. We strive to show that love to all who come to our church.*

Web Resources

- **Autism Speaks—www.autismspeaks.org**
- **Autism Support Network—http://www.autismsupportnetwork.com**
- **Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R)—https://www.autismspeaks.org/what-autism/diagnosis/screen-your-child**
- **Brain Balance Centers—http://www.brainbalancecenters.com**
- **Joni and Friends—http://www.joniandfriends.org**

We learn in 1 Corinthians 12:21-25 (NIV):

> *The eye cannot say to the hand, "I don't need you!" And the head cannot say to the feet, "I don't need you!" On the contrary, those parts of the body that seem to be weaker or indispensible, and the parts that we think are less honorable we treat with special honor…But God has combined the members of the body and has given greater honor to the parts that lacked it, so that there should be no division in the body, but that its parts should have equal concern for each other.*

CREATING ENVIRONMENTS TO INTERVENE

The complexity of the family caring for a child with ASD presents a crucial ministry area for nursing, particularly to intervene at the faith community level. We can strive to create environments in which we treat special needs children with special honor, God-like honor. Educational efforts can greatly influence the experiences of these families in order to offer a safe haven, a warm and welcoming environment, one where there is understanding of ASD and the many struggles for the children, their siblings, and their parents. From what I learned from my discussion with Mrs. Betty, a recommendation for where to begin would be to contact special needs organizations (see Web Resources) and consult with experts on how best to design and implement successful, inclusionary programs, where God's love is palpable.

I continue to be impacted by my lasting thoughts of Gabriel. Do we see God's children in our midst with ASD with love? In Luke 1:38 (NKJ), the angel Gabriel declared to Mary, "Behold the handmaid of the Lord." *Behold* in this context means to look upon with love, to see not only a surface view of what is before our eyes, but to take in fully the wonder of God and his creation.

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