

A PARISH-BASED APPROACH

HOW TO

Welcome,
Include, AND
Catechize

Children with Autism
and Other Special Needs

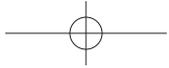


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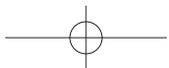
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Autism and Other Special Needs

While my expertise and professional experience is with autism spectrum disorder, the program I started at my parish has been successful for children with other disabilities as well. Disabilities come in many forms and degrees of severity. These are some of the students recently enrolled in our program:

Anne, nine years old, has very limited vision. She cannot see much of what is happening on the altar during Mass. She can read some material using a special device.

Nick, twelve, has cerebral palsy. He has significant hearing loss and is not able to talk. He gets around with the aid of a walker.

Josh, ten, has a high-functioning form of autism. His interactions with teachers and peers are a struggle for him, and he is easily distracted in new settings. He doesn't pay close attention in class, but he has above-average intelligence.

Denise, nine years old, has severe autism. She does not speak. It's difficult to know what she understands, and she frequently becomes agitated in church and class.

Mark, age ten, has Down syndrome. His intellectual capacity is limited. He has a sweet disposition. Everybody loves Mark.

All of these children benefit from one-on-one instruction. The first step is to understand their disabilities.

These impairments associated with disabilities can affect people's ability to take care of themselves, to communicate, to learn, to get around, and to live independently. Some impairments are sensory; they involve vision or hearing loss. Some are physical and can affect the ability to walk, fine motor control, and coordination and movement. Others are neurological, including autism, epilepsy, and other seizure disorders. In many cases, disabilities impair intellectual functioning.

Autism

The disability with which I am most familiar and one frequently seen by religious educators is autism spectrum disorder. *Spectrum* refers to the fact that people's impairments range from relatively mild to severe. Autism disorders are diagnosed by observing a child's behavior and development in early childhood. Autism is a lifelong disorder that can't be cured, but if correctly diagnosed, it can be successfully managed. There are currently no blood tests or genetic screenings for ASD. Autism is not a mental illness or a psychiatric disorder. Children with autism don't as a rule need medication, psychotherapy, or psychiatric treatment. They need help managing their lives.

Every person with autism is different, but there are some common traits of people with ASD. Many of these things are illustrated by the case of Anthony, a young man whom I first got to know professionally as a psychologist and later in our adaptive religious education program. Anthony's early development did not progress within the norm. He didn't respond to verbal cues very well, and he didn't seem to look at his mother very much. He didn't talk. It took Anthony's parents a while to realize that something wasn't right. Anthony was their first child; like many new parents, they didn't have much contact with other children to provide a comparison. They took him to an audiologist when he was about two years old, but he didn't seem to have a hearing problem. Then they took him to a speech and language

pathologist. Soon after, Anthony was diagnosed with autism. He didn't say more than a word or two at a time until he was nine years old. He would express his frustration at not being understood by banging his head on the desk and screaming. Sometimes he would strike his face with a closed fist. He didn't respond normally to pain.

When language finally came to Anthony, he responded very slowly. His parents, a teacher, or another child would ask a question, but it took Anthony a long time to answer—sometimes as long as ninety seconds. When the answer finally came, it was usually correct, but often the other person, frustrated by waiting, wasn't around to hear it. With his language impairment, Anthony couldn't take a standard IQ test. His teachers thought his intelligence was low, and they tried to steer him into a life-skills curriculum to learn basic skills. His parents insisted that he receive normal school instruction.

Anthony came to our religious education program when he was fourteen years old. His faith mentor was Lily, a high school freshman. In an early class, Lily mentioned the idea of sin, and Anthony asked, "Do you mean like Cain and Abel?" He proceeded in a slow and methodical way to tell the story of Cain and Abel from the Old Testament. Anthony's father and I witnessed this; we were both astonished. I had been Anthony's psychologist for five years; this was the first time I had heard him say more than a few words at a time. His father had no idea how Anthony knew the story of Cain and Abel. Neither he nor Anthony's mother had told him the story. None of us had any idea how a boy who was thought to have a significant intellectual disability could pull the story out of thin air as soon as his mentor mentioned the concept of sin.

This illustrates something that I will say often in this book: people with autism are usually unable to understand what's going on in other people's minds, but the reverse is also true. We don't know what's going on in the minds of people with autism. Anthony reminded me how

important it is, in my interactions with people with autism, to complete my thoughts and explain things clearly, even if the person doesn't give me any feedback or even seem to be listening. People with autism often know much more than you think.

Anthony was confirmed at age twenty. He learned about the Gifts of the Holy Spirit and is able to explain them. He says common prayers and can participate in some small-group activities, although he prefers to spend time by himself. He goes to Mass and appears to understand it. He receives the Eucharist regularly. Anthony is an active, involved member of his parish.

What Autism Is

Autism is a disorder of the brain's ability to process information. Sensory data gets jumbled. Language ability is impaired. People with autism can't make sense of the verbal and nonverbal cues, hints, body language, and emotions that make up the subtle web of social interaction in which we all live. The cause of autism is unknown. It may be caused by genetic mutations. It may be caused by combinations of normal genes. It may be a condition with some genetic basis that is triggered by environmental factors. We just don't know. But it's not rare. According to the March 2013 Center for Disease Control National Health Statistics Report, about one in every fifty children is affected by autism. Autism is four times more prevalent in boys than girls.

Autism is a developmental disability that manifests itself in early childhood, and it is diagnosed through the observation of poor social skills, limited communication, repetitive behaviors, and a limited range of interests and activities.

Social Skills Without direction or teaching, children and adults with autism typically show a low ability to respond to family members and a limited ability to interact with others. They often don't know or understand how to engage in simple social interactions.

Children with autism typically play alone. They don't know how to start or sometimes how to continue conversations while playing. They often can't anticipate or draw logical, parallel conclusions or deductions because of deficits in executive functioning. They often lack the ability to connect past experience with present action or to plan and organize. As a consequence, they rarely have success in reaching out to others.

Communication Skills Delayed and impaired language development is another characteristic of autism. Some people with autism never develop functional language. Many have quite limited vocabularies. Even those capable of complex speech show abnormalities such as echolalia (repeating words spoken by others), unconventional word use, and unusual inflection. As noted earlier, people with autism typically have difficulty with nonverbal communication such as eye contact; body language; and reading facial, nonverbal, and social cues.

Rigid and Restricted Behavior People with autism typically have narrow and unusual interests. For example, my friend Anthony reads obsessively about the Revolutionary War. He can recite precise details about battles and the names of officers. Many follow rigid routines and can become quite upset when these routines are disrupted. Many, particularly as children, have numerous sensory problems; for instance, they are picky eaters because of a food's texture or smell; they are bothered by materials, tags, and seams in clothing; and they are highly sensitive to noise.

Stimming People with autism often engage in "stimming." Typical stims are hand flapping, bouncing up and down, rocking back and forth, and making noise. Stimming often functions as communication; that is a way to express frustration, happiness, and excitement. It is also a reaction to stress. Children with autism are often

hypersensitive to sights and sounds, and their ability to process sensory data is faulty. So they relieve the anxiety and confusion they feel or express themselves by stimming.

Autism is a developmental disorder. The key word is *disorder*: the development of people with autism is out of order; it is not uniformly impaired. For example, a child with Down syndrome might have the developmental functioning of a six-year-old across all skill areas—social, language, behavioral—and that level of functioning will persist throughout his or her life. A person with autism can have low function in some areas and average or even above-average functioning in others. About 2 percent of people with autism have remarkable savant-like abilities. For example, a child with autism might not be able to carry on a simple conversation but can name the players on the rosters of all thirty teams in Major League Baseball or perform complex mathematical calculations rapidly without use of paper or a calculator.

Autism is	Autism is NOT
A disorder of the brain's ability to process information	A psychiatric disorder or mental illness
A developmental disability that affects social, behavioral, and communication skills	A phase that will pass
A disorder that causes variable functioning. People with autism are not uniformly impaired	A result of child-rearing, stress in the home, or evil spirits, God's punishment

This varied functioning is the reason for much heartache and frustration for parents and others who interact with people with autism. They may think, "If he can talk about cars in such detail, why doesn't he talk to me when I ask a question? If he can multiply five-digit numbers in his head, why doesn't he respond when his mother hugs

him?” But people with autism cannot do these things. Their disability is developmental. Something is lacking that cannot be supplied; they have to learn these skills that you and I have instinctually. People with autism can learn to compensate for their impairments, often by carefully following scripted behaviors, but this requires intervention.

What Autism Is Not

It's important to be clear about what autism is not. It is not considered a psychiatric disorder or a mental illness. These things are clinically significant patterns or syndromes rooted in an individual's life situation, brain chemistry, or other causes. The symptoms of psychiatric disorders usually change over time. They can usually be treated. By contrast, autism is a developmental disorder that is lifelong and relatively static.

Autism is not a phase that will pass. The neurological impairments present at birth will always be present. They will manifest differently as a person grows older, and they can often be managed, but they will not change substantially. Teachers can help people with autism work around and manage some of these impairments, but they can't help them “get better.” Even those who are very bright may return to stimming in times of sickness, grief, or severe stress.

Autism is not caused by deficient child rearing, stress in the home, or other psychological factors in the child's environment. It is not caused by evil spirits. It is not God's punishment for parents' sins. Autism can occur in any family. The condition is found in all societies and in all racial and ethnic groups.

For people with ASD, stimming and other unusual behaviors associated with autism are not intentional. They are not hostile acts meant to disrupt groups or stratagems to get out of class. They are forms of communication or reactions to excitement, stress, and confusion caused by the faulty processing of sensory input. There's nothing about it that we should take personally.

Theory of Mind and Executive Functioning

Two concepts from psychology—theory of mind and executive functioning—help us to better understand people with autism. Theory of mind is the ability to understand that other people have beliefs, desires, attitudes, and feelings that are different from one's own. It's called a theory because the mind isn't directly observable. Each of us has an intuitive understanding that we have a mind; in normal development, children soon develop a theory that other people have minds, too. This theory is shown to be valid every time we discern what someone else is thinking or feeling and are shown to be correct. Theory of mind is the basis for empathy. We cannot have intimate relationships without it.

Theory-of-mind abilities are typically impaired in people with autism. They have difficulty grasping that others think differently than they do. They don't understand that the things that happen to them happen to other people, too, and that other people are happy, sad, frustrated, and excited as a result of those things. This impairment is the source of the self-centeredness often observed in people with autism. They are quite literally stuck with themselves.

Thus, people with autism assume that everyone else shares their experiences. They feel that they don't have to explain anything because they assume that we know exactly what they are thinking. (What else would we be thinking?) A man doesn't have to explain why he is late for work because his boss already knows why. A child won't tell her mother why she is angry because her mother already knows. A boy assumes that everyone is as interested as he is in the rosters of Major League Baseball teams and the details of Revolutionary War battles.

We "mind read" all the time. We read faces, pick up cues from body language, and attend to nuances of tone when other people are speaking. We judge when it's appropriate to smile, frown, laugh, and speak. Imagine what life is like for someone who can't do this. They might talk endlessly about their favorite topic long past the point at which a

polite listener has communicated in a dozen nonverbal ways that it's time to move on to something else. They might laugh at a funeral, fail to say thank you for gifts, or get angry when they are called for dinner.

Autism and Theory of Mind	
Individuals with autism often struggle to take another's perspective or "put themselves in another's shoes"	How Catechists, Teachers, and Others Can Help
Difficulty explaining their own behavior	Teach the concepts of emotions and feelings.
Difficulty understanding emotions	Teach awareness that others have their own state of mind.
Difficulty predicting others' behaviors or emotional states	Teach how to read nonverbal and social cues.
Problems understanding perspectives of others	Review different perspectives.
Problems inferring the intentions of others	Practice social situations.
Lack of understanding that behavior impacts how others think and feel	Role-play/rehearse.
Problems with joint attention and other social conventions	Engage in collaborative, sensory-friendly games or activities.
Problems differentiating fact from fiction	Support abstract concepts with scripts and visual aids.

Social life is chaotic and painful for people with theory-of-mind deficits, so they learn coping strategies. One strategy is to adhere to rules and routines. When you don't know what's expected of you, clinging to an established routine makes life more predictable and less surprising. People with autism often develop highly detailed rules and become very upset when they are asked to alter them. Another coping

strategy is to imitate what others do in social situations. This helps, but because the person doesn't understand the nuances of social behavior, imitation is a partial solution at best. I observed an embarrassing example at a Baptism where I presided. After the ceremony, a young man with autism watched carefully as family members came up to the mother and greeted her with hugs and kisses. The man was not part of the woman's family and had never met her. Nevertheless, he approached the woman and tried to kiss and hug her; he was shocked when she pushed him away. He had made a mistake in guessing that hugging and kissing is "what you do" at Baptisms.

Unable to recognize linguistic nuance, people with autism tend to take words literally and believe everything they are told. This tendency, combined with blindness to social cues, can cause social disasters. A person with autism might ask an overweight woman why she is so fat or a bald man why his head is shiny. They often do not get jokes or understand lying and deceit. This can have difficult results. I have worked with autistic young people in a juvenile prison in Pennsylvania. A number of them had done exactly what their "friend" told them to do, having no idea that it was illegal until the police arrested them.

Another disability, one that can be even more troubling, is impairment of what psychologists call executive functioning. This is the ability to manage cognitive processes such as memory, attention, problem solving, reasoning, and language and use that information to manage the future. All these processes must work together if a person is to learn, communicate, and work. Executive functioning allows us to think abstractly. It's the ability to be flexible and adapt to changing conditions.

For many people with autism, this management is jumbled and disorderly. They have difficulty understanding cause and effect, that something they do now will have an impact on later events. That makes it very difficult to make any kind of plan. They have difficulty

generalizing; they experience every situation as novel. A child might see that two plus two equals four, but not that four can also be obtained by adding one and three or four and zero. This impairment makes relationships difficult. An autistic boy with a crush on a classmate might not be deterred when she tells him to go away. Every day is a new day. He might approach her again and again, not understanding that a firm rebuff means that she's really not interested in him.

The Autism Spectrum

In describing the manifestations of autism, I've used many qualifying words such as *frequently*, *often*, *sometimes*, and *might*. That's because it's hard to generalize about the symptoms of

Assume nothing, and
build on strengths.

autism. Autism is diagnosed by observing behavior, but the observed behavior varies tremendously from person to person. I've worked with thousands of people with autism. No two are alike. Thus, we have something of a paradox. The disabilities of autism are permanent, but in almost all cases, the weaknesses are accompanied by strengths. A child's intellectual abilities may be low, but she may have relatively strong language. A boy might have fairly good social skills but also engage in severe stimming. It's important to carefully observe children with autism. Assume nothing, and build on strengths.

Psychologists account for the variability of symptoms by speaking of autism spectrum disorders. At one end of the spectrum is what used to be referred to as Asperger syndrome, a high-functioning form of autism. Children with this condition do not have problems with early language development and do not show the cognitive deficits that other people with autism have. They do show the other problems associated with autism: poor social skills, repetitive behavior, an attachment to routines and rituals, and subtle problems such as avoidance of eye contact and odd gestures. Many higher-functioning children aren't

diagnosed for many years because their language and intellectual development are typical.

Pastoral Care of People with Autism

Pastoral care of people with autism begins by making the parish a comfortable, welcoming place. Many parents of children with autism are reluctant to bring their children to Mass or religious education. They worry about how their children will cope with an unfamiliar muddle of sights and sounds and with contact with new people. They fear that their children's stimming will upset other parishioners. Pastoral ministers need to seek out these children and their families and assure them that they will be welcome.

Of course, pastoral ministers need to follow through on that promise. In my parish, we make people with autism visible. A man with autism in his forties serves as an usher. Each week it's his responsibility to fill the holy water fonts, help with the weekly collections, and bring the food basket to the altar at Mass. A man with severe hearing loss is a lector. A woman with Down syndrome serves at weekday masses. Teens with autism serve as teachers and aides in my religious education program. Visibility builds familiarity. When people see an usher with autism, other people with ASD feel comfortable at Mass, and it gets easier to invite them to participate in other parish activities. This is great.

I encourage clergy to talk about autism and other disabilities from the pulpit. I have done this in many parishes, and I have found it to be a highly effective way to open the door. It's helpful to demystify the disabilities and their associated behaviors. This fosters a people-first attitude where we see a person who happens to have a disability rather than a disabled person. When I talk about autism in parishes for the first time, I make it a point to go directly to stimming—the core concern for many in the pews. I explain that things like noises, hand

flapping, and bouncing are behavioral responses to what people with autism are seeing and hearing. I point to the stained-glass windows, gleaming on a sunny Sunday morning. I mention the sounds of the organ, the flickering candles, and the colorful vestments and ask people how they would feel if they didn't have words to describe the emotions these things aroused in them. That's the predicament of people with autism: they can't express happiness and excitement (or anxiety and boredom) in words, so they use actions.

It's a truism that there is no substitute for personal, individual attention when it comes to pastoral care. This is certainly true for parish ministers relating to people with autism. Individual attention is the cornerstone of the religious education program that's described in this book. It needs to be the foundation of other pastoral initiatives as well.

A story will illustrate the point. I discovered that a young mother of two boys with autism did not come to Mass because her sons couldn't sit through it. They reacted to the sights and sounds of Mass with severe stimming. Over eighteen months, I worked with the mother to accustom her sons to Mass in a process of gradual familiarization.

We started by walking around the church before Mass began. The boys, who were extremely attuned and sensitive to sounds, plucked on the piano keys. One of them played short melodies. For weeks, the mother and her sons sat in the back of church and stayed a little longer for each Mass. At first they heard the opening announcements and left before Mass began. Then they stayed through the opening hymn, then the Liturgy of the Word. It took four months for the boys to be able to stay through the reading of the Gospel. The homily was difficult for them to get through. The boys like predictability and routine, and homilies are hard to predict. Some homilies are long, some are short, some are interesting, and some are dull. It took several more months for the boys to be able to get through the homily comfortably.

We proceeded through the Mass at a steady pace week after week. The boys were being prepared to receive the Eucharist, and they were eager to see this part of the Mass “for real.” In class they practiced receiving the unconsecrated host. Often their teen mentors would sit with them at Mass. It took nearly eighteen months for the boys to be able to attend an entire Mass from opening announcements to closing hymn. They don’t just sit through it; they participate. They receive the Eucharist, they pray, they understand what is happening on the altar. The boys (and their mother) are participating in the life of our parish to the extent that they are able. That’s what good pastoral care can and should accomplish.