



PASTORS: YOUR PIECE OF THE AUTISM PUZZLE

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Forward

by Jim Esmeier, IDDM Coordinator

This paper has been under development for some time. It was written originally by Pastor Tom Gumm and presented to the Puget Sound joint circuit meeting at Holy Trinity, Des Moines, Washington.

Our Lord saw additional uses for it when he introduced Pastor Gumm to me via a phone call seeking a former acquaintance. As we talked, I learned of Pastor's experience with Autism Spectrum Disorder (ASD), particularly those identified at that time as having Asperger Syndrome. Pastor Gumm told me about his son with this condition and of his *Aspie* support group of 20 or more people in the Seattle, Washington, area.

I shared the work of our Intellectual and Developmental Disability Ministry (IDDM) and its impending retreat for parents who have children with special needs. The retreat name, *Give me A Break*, appealed to Pastor Gumm, and he expressed interest in being on our IDDM committee. As the committee members were deliberating his offer to serve, Pastor Gumm sent me an e-mail that showed an incredible amount of sensitivity and insight into the needs of parents and the value of the committee's retreat.. The rest is a blessed history that includes Pastor's sharing of this paper.

In addition to the original paper, Pastor Gumm asked his support group what advice they would give pastors and teachers. Their response has been added to the original document making this paper even more authentic, coming from *real people* rather than conclusions drawn from research.

While we were working on the revisions of this paper, tragedy struck Newtown, Connecticut. When a crazed young man shot and killed 24 students and teachers at Sandy Hook Elementary School, it was revealed that the young man had a diagnosis of autism. Advocates were quick to point out that people with ASD have no tendencies to commit such heinous acts...but, Pastor Gumm said one of his students relayed the taunting he had received from a person who said, "*Are you going to shoot us too?*"

Brothers and sisters in the Christian faith, this topic is vital to our understanding and needs to spur us to action. Pastor Gumm is leading the way on our IDDM Committee. Please learn with us and share your love based on knowledge of *all* the members of the body of Christ.

Autism Spectrum Disorder: Please Accept Me, for God Made Me Different.

Presented by Thomas Gumm on November 14, 2011,
for the Puget Sound joint circuit meeting at Holy Trinity, Des Moines, Washington

His disciples asked him, "Rabbi, who sinned, this man or his parents, that he was born blind?"
"Neither this man nor his parents sinned," said Jesus, "but this happened so that the works of God might be displayed in him. (John 9:2,3)

Not everyone speaks WELS

The young man who came to church stood to one side and seemed to watch everyone. He did not make eye contact and he said very little. He seemed like he was studying everyone. When a baby would cry or a loud laugh boomed, he seemed to wince in pain. Around certain lights he seemed to shade his eyes. Two children were chasing each other and they bumped into him. He seemed very uncomfortable. During the worship service he kept his head down. He sat in the back near the door. He seemed to fidget in the pew. His hands moved in a rhythm and a pattern. It almost seemed that he was distracting himself. Someone finally got a chance to visit with him and asked him a few questions, including how he liked the service. He seemed to lock up. The words just didn't come. He seemed almost agitated as he struggled for words. Without saying anything, he walked away and disappeared out the door. You thought, "This one is an odd duck. He is strange."

Introducing Autism Spectrum Disorder

You have just witnessed a standard type of interaction with a person with Autism Spectrum Disorder, or ASD. (*The former classification of "Asperger Syndrome" was changed in 2013 to a level 1 "Autism Spectrum Disorder" in the publication, DSM-5, by the American Psychiatric Association and will be referred to as ASD.*) If this is his first time at your church, he is overwhelmed with the new. He is taking in so much sensory information that he is unable to feel comfortable, react, or hold a discussion. The florescent lights are causing him to have a migraine headache because his sensitive eyes can see each pulse of light go through the tube. Any sound over 85 decibels causes him pain, for he can feel the hairs in his ear getting damaged from the volume of sound. He hates to be touched because it may be painful. When you talk with him he can't look at you. His eyes and mind are taking in so many cues from your face, your voice inflection, and the way you stand that he feels overwhelmed---so much incoming information for his brain to process that he can't think about your words much less a response. He feels that a fire hose worth of information is coming into his senses and that he is drowning. As he becomes overwhelmed he feels lost and confused and begins to lock up. He is frustrated, panicked, and embarrassed. He is thinking, "RUN!!!"

Intense sensitivity

Personal issues

For the last eight years I have been learning all about ASD. My son was diagnosed with Asperger Syndrome--now ASD--eight years ago. Five

years ago my son, my wife, and I began attending a support group for persons with level 1 ASD.

This group lost its lease at the senior center and came to me to find a new location for their meetings. Grace Lutheran Church became the group's location. The group has developed into a socialization gathering in which 18-22 people come talk on one or two topics at each meeting.

General characteristics of persons with level 1 ASD

Because level 1 Autism Spectrum Disorder (ASD) was previously called Asperger Syndrome, many people with this level of ASD still call themselves "aspies." (For purposes of this writing, they will be called by the newer designation, *persons with ASD*. In this paper, "persons with ASD will specifically refer to persons with level 1 ASD, formerly called Asperger Syndrome.) Persons with ASD call people without ASD "neurotypicals" or "nypicals." In discussions with my ASD support group, I explained what I understood and they quickly corrected me.

Strong feelings

I always thought that persons with ASD had limited feelings. I was told that on the contrary, they have super-strong feelings that cannot be expressed in words. Most of us learn how to describe feelings by age 20. For a person with ASD, it may take 40-50 years to be able to put emotions into words. Likewise, while we typically begin to notice people of the opposite sex at about 14-16 years old, persons with ASD may be between 28-30 years old when beginning to notice the opposite sex. It is at this age they begin to use makeup, care that what they are wearing is fashionable, and want to date.

Slow mirror skills

When a child is born with ASD, some scientists believe their "mirror neurons" (neurons that fire both when someone performs an action and when the person observes the same action performed by another) are very slow. Normally, if you smile at a child, that child will smile back at you. The child with ASD may not smile at all or may only give a slow, weak response. As you play with children with ASD, it may seem that they don't respond. They do, but much slower than most children do. Some researchers believe that mirror neurons help children develop social skills by imitating what adults and other children do. These mirror skills take much longer than usual to develop in a child with ASD, so from little on, persons with ASD often will not understand social rules. Others will need to explain the rules or situation for them to understand.

10,000 social rules

When working to help persons with ASD understand social rules, it is important to explain the rules in a very gentle and straightforward manner so that they will not be embarrassed. They truly do not understand and frequently do not see the need for certain social rules. Counselors today have 10,000 social rules that they can have persons with ASD memorize to help them through life. Persons with ASD may read many books about reading a person's facial expression, their breath rate, their twitches in their eyes, and the pulse of blood in the neck so that they can figure out if a person is lying, making fun of another, being honest, and the like. They may also read books on body language. If a person with ASD is standing to the side of a room, that person may be studying other people to learn how his or her own body language and

Desire for predictable outcomes

facial expressions should be, or how to act in a certain group. Some persons with ASD will practice in front of a mirror so that people can read them correctly.

Children growing up with Asperger's (ASD) may want to understand things completely and know all the rules before they are comfortable playing a game. They want to know all the predicted outcomes to each move, each rule and the strategy of the game. So they stand off and memorize. Once they start learning a game or looking at an item in nature, they may not be able to turn off their thinking about it, which can result in insomnia. (My son once stayed up four full days until he could figure out the volume of a three-dimensional cone.) Growing up is hard enough for children without ASD; it is much more difficult for a person with ASD. They are different. Children pick up quickly on differences and tend to make fun of them. Children with ASD may feel rejected, assaulted, and destroyed. They just want to be accepted and have friends. For much of their life they may feel alone and very paranoid.

School like a combat mission

Each day children with ASD go to school, they can feel as if they are going out on a combat mission, expecting at any turn of the hallway to be assaulted and attacked. They have little or no comfort at school. They endure it. They are fodder for teasing. They act differently and are rejected by the other kids. For some, going to school would be hell if it weren't for math and science and books or computers. Knowledge is the safe haven. The glorious details engage their mind, open understanding, and distract them from all the other pain. Knowledge is logical. Social rules are not logical. If something isn't logical, the person with ASD tends to ignore it or defy it; it is not worth wasting time on it.

Routine the best friend

Routine is the best friend of a person with ASD. Let me repeat this. Routine is the best friend of a person with ASD. Since so many things in life are painful or overwhelming to them, they need routine to know what is coming, as well as when and how to react to it. To avoid pain many of them develop obsessive-compulsive routines or actions. Change is very difficult for persons with ASD. The best thing a teacher or pastor can do for them is follow a routine almost to the minute. Routines help persons with ASD feel more comfortable and better able to participate. If you want a person with ASD to be able to discuss a topic or develop an opinion, give that person advanced notice of the subject. Persons with ASD may need about a week to think things through well enough to be able to talk about that subject. At our ASD support group we give two weeks to prepare two topic questions. Our participants have so much to work through in their heads that doing so takes two weeks.

Advanced notice needed

Pain avoidance

Because so much is painful to persons with Asperger's, they may manipulate people and their environment. To avoid the pain of having other children be mean to them, they may develop strategies to outthink them or even humiliate them. They may also keep people at arms' length to avoid being hurt, refusing to trust anyone. This lack of trust may lead them to constant looking for scams or brainwashing. From not being accepted for who they are, they may become very bitter toward people without ASD ("nypicals"). It has taken some of the participants in my support group three years to trust me. They will test me little by little. At first they want to argue with me to show that they have superior

Lack of trust

intelligence. When they see that I don't get defensive but honestly care for them, they begin to change. As with most people, the more you help persons with ASD feel accepted, the more they will relax and open up. Most persons with ASD want to be accepted and have friends, even though they are different.

Implications for Pastors and Teachers

How does this information help us as pastors and teachers work with people who have ASD? It is important to remember that having faith can be very difficult for them since their ability to handle emotions is slow-developing. Persons with ASD need experience and words to help them connect concepts. Faith may not seem logical to them, so many reject the idea, thinking, "Give me proof. Show me by science." They demand physical evidence, which their minds can easily absorb. Anything emotional takes a longer time and will have to be displayed for them.

Because of the many things that give persons with ASD pain, often they do not fully understand love. Many persons with ASD think that God hates them because he made them to experience so much pain. They think, "He made us wrong. He hates us. We are not accepted by people, so God must not accept us either." The actions and words of your members will have a great impact on teaching people with ASD love. Will your people tease them, think they are strange, or stay away from them? When they ask a question in your Bible study class or your confirmation class, will you give a sigh before giving an answer?

If you have student with ASP, you can't teach that person like everyone else. You will need to base your teaching method on the student's interests. Here are two examples:

A ten-year-old girl with ASD attended a vacation Bible school. The teacher was teaching the account of Noah's ark. The teacher wanted to get through the lesson, but the girl wanted to know more about the animals. (One of her loves and areas of interest were animals. She could have spent the next three days talking about animals.) The teacher was on the time clock to get the class from point A to point B. In her frustration she corrected the girl for wasting all the other children's time and told her to stay on the points of the story. The girl went home and told her mother that the both teacher and the other children were mean and that they did not want her there because she was wasting their time. The girl never went back to a church until she came to my ASD support group meeting. She is now 28 years old.

A strapping, big, red-haired man named Daniel told me a story about his experience with church. Daniel wanted to go to church to find out about God. Daniel had lots of questions and he did not understand many things about God. Daniel needed time to work things

Faith takes time to develop

May think God hates them

Need to see and hear acceptance

Need teaching based on student's interest

Take time to develop concepts.

through. Well, he did not react as the others did. He asked lots of questions. He seemed to have lots of doubts.

Never reject the student because he learns differently

When the people at the church saw these things, they figured he was there to test their faith and that Daniel had come to mock them. They determined that Daniel was from the devil. They told him he was going to hell because he questioned God. After about six times at our ASD support group meeting, he stayed after a meeting and told me this story. Then with an intense expression on his face, Daniel asked me point blank, “Am I from the devil and am I going to hell?” For the next hour and the next six months we talked about God’s grace, God’s love, God’s acceptance, the work of Jesus, and many other biblical teachings.

Here are some things to keep in mind as you work with persons with ASD:

Know students well

1. Get to know them. Ask very specific questions to get detailed information so that you understand each person’s unique set and full range of sensitivities. No two person’s with ASD are the same. Many books about persons with ASD are general and combine multiple sensitivities into one person, as if one description fits all. Beware of over-generalizing. Recognize that a person with ASD may excel in one type of learning (visual, auditory, or tactile/kinesthetic) but not in all aspects of that type of learning. For example, a student may excel in colors, but not in art. A student may be good at mechanical assembling but can’t sculpture clay with his or her hands. Seek specifics on strengths and challenges.

Tell why

2. Tell them why you do things. Do not expect them to read you. They do not understand social rules. They may assume that you are doing things to hurt them. Do not let them assume your motives; tell them your motives clearly.

Accept each other

3. Remember that it is imperative for them to accept you and you to accept them. I can’t say this strongly enough. They may have felt let down or deceived for most of their lives. They want to hope, but they are terrified to be open. They need you to model the love of Christ. They need your people to model the love of Christ. You have to get through the great wall of their defense and give them a safe place to relax and learn.

Reduce stimuli

4. Provide ways to reduce stimuli. If persons with ASD are overwhelmed by their surroundings—that is, sound, lights, people too close to them, no routine, etc.—they may need a place to decompress. Most persons with ASD have a “decompression cave.” This is a place with no light and no sound. They literally cut off all stimuli to help deal with the overwhelming. Some parents buy “musician’s ears” for their children with ASD. A musician’s ear is a hearing device that lowers all sound above 85 decibels. This cuts out the pain. So if you have a loud organ or a powerful P.A. system, the person with ASD may need to take measures to lower the sound. (One woman who comes to our support group sits in the other room since her hearing is so sensitive.) If you notice that your student with ASD is beginning to lock up from being

overwhelmed, encourage the student to go into a quieter study place to decompress or to work.

Teaching tip: Have each student in a class keep a folder on top of his or her desk. If any student, (not just one with ASD) becomes overwhelmed, he or she could put the folder up on the desk as a signal that five minutes of downtime is needed to deal with emotions. The teacher should not ask what is going on but simply mark the time. After five minutes the folder has to come down. This way no one is singled out, and all students can have folders for a time out when needed.

Desensitize students to various people in a work group

5. Be cautious when doing cooperative group work. At first, carefully pair students with ASD with dedicated, reliable students to teach them equal levels of teamwork. Gradually teach the student to work with groups that are less even (such as those they will work with in society). Explain to students with ASD that they are going to be paired with people who may not as willing to do their work and may not reliable. Teach the students how to deal with lazy workers or workers who want to take advantage of them

Don't hold students back

6. Allow for students with advanced abilities to work at their level. Many students with ASD are gifted in other areas. Allow them to use their God-given gifts rather than holding them back because of the ASD or to keep everyone doing the same work.

Allow more time for test taking

7. Accommodate special test-taking needs. Students with ASD tend to be detail-orientated. This means that when it comes to test-taking, they need to figure out the generalized nature of most test questions so that they can give the right answer from the hundreds of details they know. The result may be not finishing any timed test on time. Allow more time, not because the student doesn't know the material, but because he or she has to figure out which exact detail each question is seeking.

Beware of high stress levels

8. Help keep stress levels low. People with ASD tend to be terribly stressed most of the time. They are spending so much energy dealing with their sensitivities that they have a limited amount of energy left to do things or deal with situations. Deadlines are very hard on them. For a person with ASD, sometimes a game-like learning environment can reduce the stress and increase participation. (My son could handle tests because he looked at them as a game. He had to finish before anyone else! But daily work was too stressful for him to do.) If you set up a game to make learning less stressful, make sure the rules are clear.

Recognize talent and emphasize each person's importance

9. Encourage individuals with ASD to believe that they are needed for their talents and gifts, both in society and in the church. Remind them that God has a plan for each person, and everyone has a role to play in God's kingdom. With this attitude shift persons with ASD will try harder to fit into society, serve the Lord, and grow to their full potential.

Don't over-emphasize ASD

10. Don't over-emphasize the ASD. It may be necessary to talk to the other students about the unique needs the student with ASD has, but don't keep bringing it up. As much as possible, treat the student with ASD like

all the others or the ASD will be the only identifier that student will have with the other children.

Use technology to compensate for note-taking struggles

11. Recognize that handwriting and note-taking may be struggles for the students. Make accommodations as necessary. You could have a friend take notes for the person with ASD. Use Power Point presentations instead of just lectures to help all the students remember materials better. You may even wish to purchase “Dragon Naturally Speaking” software. With this software the teacher wears a headset and a computer puts into type all the words spoken. At the end of the lecture the student hits “save” and “print,” and out comes the entire lecture as it was presented in class. (Note: Some of the new iPad software may do an even better job than “Dragon Naturally Speaking.” Always search for the latest technology and compare.) In general, however, lecture is often the worst teaching method for students with ASD—and for many other students as well. Pastors need to consider this as they are planning their catechism classes, which have traditionally been taught using lecture. The lecture format may be easiest for the busy pastor, but with extra time put into the presentation, all the students might remember the precious truths of God’s Word better.

Avoid lecture

Consider social stories

12. Consider using social stories when teaching a person with ASD one-on-one. Social stories are special stories used to teach social skills to persons with ASD, especially children with ASD. These social skills tie in well with class behaviors you wish to encourage and ways that we can keep God’s Ten Commandments. However, do not trust all Internet websites that have social stories; learn the do’s and don’t’s of using social stories properly, as listed in the third resource provided at the end of this paper.

Accept service dogs

13. Be accepting of service dogs. It is becoming more and more common for persons with ASD to use service dogs. These dogs are highly trained. Allow them in your church, and ask congregation members not to pet a service dog unless the owner gives permission.

Patiently model love

14. Be patient. Persons with ASD will challenge you not because of malice, but because they want a greater understanding of the topic. Accept them as a marvel of God’s handiwork. Model love. Give examples of faith or any other emotion that comes up in a lesson. Be prepared to take side trips on a topic. If a subject normally takes 20 minutes to teach, double the expected time with a person with ASD in the class. Work with your people and your children to accept people with ASD and to be their friend; they need our understanding and our help. Remind them of Jesus’ words: “By this everyone will know that you are my disciples, if you love one another” (John 13:35).

Resources

Just Give Him The Whale!: 20 Ways to Use Fascinations, Areas of Expertise, and Strengths to Support Students with Autism, by Paula Kluth and Patrick Schwarz. (2008. Paul H Brookes Publishing Co.)

When learners with autism have deep, consuming fascinations trains, triangles, basketballs, whales, teachers often wonder what to do. This concise, highly practical guidebook gives educators across grade levels a powerful new way to think about students obsessions as positive teaching tools that calm, motivate, and improve learning. This book is especially to teachers of students from early elementary school through the start of high school.

Asperger's: What Does It Mean to Me?, by Catherine Faherty. (2000. Future Horizons)

Each chapter is divided in two parts: the first part, "The Workbook," is for the child to complete by writing or highlighting "What is True for Me" in lists of simple statements. The second part, "For Parents and Teachers," contains helpful tips/information for the adult who guides him through the exercises. The book will provide insight into your child's mind, and make him/her more self-aware, learning what autism means in relation to crucial areas of his/her life: friendships, fears, abilities, and much more.

The New Social Story Book, by Carol Gray. (2010. Future Horizons)

Winner of an Outstanding Literary Work of the Year Award by the Autism Society of America, this 10th Anniversary Edition of *The New Social Story Book* offers over 150 of the most requested Social Stories, each one professionally written by Carol Gray. But it doesn't end there Carol also teaches you how to write Social Stories yourself! Years of experience and trial-and-error have led to updated Story guidelines. Carol explains her fine-tuned process in the included ten-step learning module for parents and teachers.