

CHILDREN WITH AUTISM SPECTRUM DISORDER, THEIR FAMILIES, AND THE
WORSHIP SERVICE

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Abstract

Autism Spectrum Disorder (ASD) is being diagnosed more often every year throughout the entire world. This means that more children with this disorder and their families will be members of our congregations. This disorder brings with it special difficulties in the worship service. When a child with ASD joins our congregation it is important first for us to understand what this disorder is and what it is not. It will then be wise to apply those findings to situations that play out in the worship service. Finally congregations will want to learn how to integrate these people into their worship as seamlessly as possible, understanding all the while that this will take patience and a humble, loving attitude.

Introduction

By now everyone has heard of it. Most of us have seen it in a movie or on the news. Many of us have known someone with it. Autism is no longer something unknown or surprising. On the contrary, the talk now is about how many more people are diagnosed as having Autism every year. In fact, from 1990 to 2008 there was an increase of Autism diagnoses of 172 percent.¹ With this increase of awareness and the appearance of an increase in cases it seems pertinent for Christians to seek for answers as to how to follow the Great Commission² for these individuals. That however is too large a topic for this thesis.

Over the previous year I have read about multiple “horror stories” of children with Autism and their parents in regard to their experiences in worship. Each situation ended with the family leaving the particular congregation and joining a more accepting congregation. While we in the WELS hope that our commitment to the Word and to the truth of that Word³ would make it so that our members who run into these situations at least begin attending another congregation in our fellowship where they will receive pure teaching and preaching, we are fooling ourselves if we think that is what will happen every time. Better is to educate our people about Autism so that the sinful nature cannot grab onto ignorance and use it to tempt us into mistreating fellow sinners for whom Jesus gave his life.

This is where this paper aims then: to educate the reader about the condition commonly known as Autism, though more appropriately called “Autism Spectrum Disorder” (ASD), and by education, increase awareness and understanding of behaviors that may be exhibited by children with ASD during worship. The hope will be that with this new understanding the pastor, worship planner, and congregation will increase their flexibility in worship planning and preparation so that children with ASD and their parents A) do not get caught up in these “horror story” situations, B) encounter a welcoming environment at worship, and most importantly, C) are able to worship on an equal level as all other Christians, thus receiving the blessings of worship God promises.⁴

¹ Uta Frith, *Autism: A Very Short Introduction* (New York: Oxford University Press, 2008), 39.

² Mt 18:16-20

³ Jn 17:17

⁴ For a short description of the expectations and blessings of worship please look at section 2

Part 1: What is Autism?

Section A: A Brief History of Autism

Autism is a new word for an old condition.⁵ “The term Autism comes from the Greek word *autos*, meaning ‘self,’ and *ismos*, referring to ‘action’ or ‘state.’ It originally meant (circa 1912) extreme self-absorption that prevented the individual from extending himself or herself to other people, and hence being removed from important social learning experiences.”⁶ Since those early years of identifying Autism as something of its own multiple ideas regarding its cause have been posited and tested. These ideas have led to many misconceptions and misunderstandings regarding this disorder.⁷ One of the early ideas regarding Autism is cited by Uta Frith:

*A powerful myth arose (through the early days of identifying Autism). This is how it goes: some children experience a rejection so traumatic that there is no way but to withdraw from the hostile world outside. This withdrawal is so complete that nothing can reverse it, except lengthy psychotherapy. Only psychotherapy did not produce the desired effects.*⁸

This type of hypothesis being set forth and then proven false can still make its way into the public psyche and stick around long after the idea has been shown to be wrong.

Over time it was found that Autism would not be so easy to pin down to a certain set of behaviors every time.⁹ Even in the most recent update of The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) the definition of what fell within the bounds of the “autistic spectrum” changed from DSM-IV. Autism is now officially called “Autism Spectrum Disorder,” indicating that there is a range of behaviors and severities that encompass “Autism.”¹⁰

*It used to be assumed that Autism almost always went together with learning disability, or mental retardation, both terms indicating brain pathology associated with low measured IQ. Recent studies have changed this view. Now the spectrum of autistic conditions fully embraces those who have no intellectual impairment when assessed by standard intelligence tests. At present the diagnosis of Autism combined with low intellectual ability is made in about 50 percent of cases, and in 50 percent is combined with average or even superior levels of intellectual ability.*¹¹

⁵ Frith, 20

⁶ Albers, Robert H., William H. Meller, and Steven D. Thurber, *Ministry with Persons with Mental Illness and Their Families* (Minneapolis: Fortress Press, 2012), 159.

⁷ This will be explored in section 1b

⁸ Frith, 20

⁹ Frith, 21

¹⁰ Frith, 4

¹¹ Frith, 25-26

Along with this newer phenomenon of diagnosing persons with all levels of intelligence with ASD is also the ability to diagnose both young and old with ASD.¹² It used to be that only young children were diagnosed with ASD, but after observing children with ASD grow into adulthood researchers learned that ASD is a lifelong situation, even if those children may learn coping and compensatory strategies over time.

Perhaps the biggest thing we can learn from looking at the history of identifying and classifying ASD is that above all else people with ASD are still *people*. Why was ASD ever identified? Why is there research on the topic? It was the parents of children with this disorder who pushed and encouraged and demanded that something be done to help their children.¹³ They lived with these children every day. They saw the problems firsthand. More than that, they saw the precious people their children were and they loved them. For us Christians as we deal with children who have ASD in our congregations let us too see them as children of God first and then recognize that they may need us, out of love, to accommodate some needs that the rest of us don't have, the same way we would accommodate a person in a wheelchair or who was blind.

B: Misconceptions Pertaining to Autism Spectrum Disorder

With the relative newness of ASD being diagnosed and its even newer procession into the language of the general public, it is no surprise that many misconceptions would arise regarding people with ASD. This problem is only compounded when the definition of what falls within ASD is shifting relatively regularly. One of the first things that this paper can accomplish is to clear up some of the basic misconceptions that people sometimes have about ASD.

Perhaps the most pervasive misconception regarding ASD is that people believe that there are just a few certain and definite things that mark it and everyone who has it is the same. This could not be further from the truth. A famous saying about people with ASD is, "If you meet one person with Autism, you've met one person with Autism." The point is that one of the biggest mistakes you can make is to expect the experience you had with one person with ASD to be repeated when you meet another person with ASD.¹⁴

If you are like me then the first time you became aware of ASD was through a face to face encounter and that shaped your definition of this disorder for a time. If that was the case, my guess is that it was a rather memorable experience. If that initial experience was with a person

¹² Frith 41

¹³ Frith, 23

¹⁴ The reasons this assumption is so wrong will be more fully expounded in section 1e

who had ASD and also had a form of intellectual disability¹⁵ then perhaps you, like me, thought that “Autism” meant that this person also certainly had an intellectual disability. This assumption was overturned by studies conducted in the 1960s.¹⁶ It is true that ASD is often accompanied by intellectual disability,¹⁷ but it is now recognized to be something that sometimes happens alongside ASD, but is not necessary for an ASD diagnosis.

Standing on the opposite corner of this misconception about intellectual disability is the misconception that all people with Autism are savants or are exceptional in some way. There are a few understandable reasons for this misunderstanding.

In society an oft-cited reason for this view of Autism is the popular 1988 film “Rain Man,” starring Dustin Hoffman and Tom Cruise. In the film, Hoffman plays Raymond Babbitt, who has Autism and has incredible memory abilities. The character is even inspired by a real life savant, Kim Peek - although he did not have ASD.¹⁸ Nevertheless, it makes sense that some people who have only knowingly had contact with a person with Autism through this film might expect all people with Autism to be savants.

Another reason that could account for this ill-conceived conception of people with Autism is that when Asperger’s Syndrome, which is now classified as a form of Autism,¹⁹ became a popular label in the early 1990s it was mixed up with the old idea of a “mad genius.”²⁰ This persists today, seen even in the popular BBC show “Sherlock,” where Dr. Watson refers to Holmes as having Asperger’s,²¹ though that is certainly not the case.

¹⁵ I will use this term in this paper, as it is what is used in DSM-V and the term “retardation” has been consistently used in the general populace in a way that has now begun to cause pain and distress to those with intellectual disabilities and their families. Keep in mind that I will quote some authors who still use the term “mental retardation” in the most professional sense.

¹⁶ Frith, 21

¹⁷ American Psychiatric Association, *The Diagnostic and Statistical Manual of Mental Disorders Ed. 5* (Washington DC: American Psychiatric Association, 2013), 31.

¹⁸ Berit Brogaard, Psychology Today. “Kim Peek, The Real Rain Man.” Last modified December 11, 2012. Accessed December 1, 2014. <http://www.psychologytoday.com/blog/the-superhuman-mind/201212/kim-peek-the-real-rain-man>.

¹⁹ DSM-V, 53 This is a big change. The Autism Research Institute had this to say on the change, “The removal of the formal diagnoses of Asperger’s Disorder and PDD-NOS is a major change. People who currently hold these diagnoses will likely receive a different diagnosis when re-evaluated. This has the potential to be confusing for parents of children with these diagnoses as well as children and adults who identify strongly with their diagnosis.” “Updates to the APA in DSM-V – What do the changes mean to families living with Autism?,” DSM-V: What Changes May Mean, accessed February 17, 2015, http://www.autism.com/news_dsmV.

²⁰ Frith, 21

²¹ Sherlock, “The Hounds of Baskerville,” episode 5 [season 2, episode 2], May 13, 2012.

What is difficult about this particular misconception is that it is not fair to people who have ASD. There certainly are people with ASD who have savant abilities, but it's only 10 percent of people having ASD.²² So to expect these beyond extraordinary abilities every time you meet someone with ASD sets them up to be a disappointment and that simply is not fair. Still, don't let it be lost that even most people with ASD do have exceptional abilities that aren't necessarily "savant," such as completing jigsaw puzzles with the pieces upside down, quickly finding Waldo, and about 30% of all children with ASD have absolute pitch.²³

A fourth misconception is to assume that all people with ASD are altogether incapable of social interaction. As will be delved into deeper later, one of the key diagnostic factors of ASD is "persistent impairment in reciprocal social communication and interaction,"²⁴ but this does not mean that there can be no social interaction. First of all, people with ASD certainly do have feelings, even equally as strong feelings as a person without ASD, but they may not be able to express those feelings with words in the same way.²⁵ Frith also points out this misconception then shares a poignant story:

*It would be a mistake to believe that people with Autism have no social understanding at all...Four-year old Sebastian was almost totally self-absorbed. And yet, one day his mother observed that he brought a blanket to cover her when she was resting on a sofa. Examples of kindness that transcend the typically strong egocentrism of people with Autism spectrum disorders are not common, but they exist. Likewise, examples of empathy exist, even though a lack of empathy is frequently seen as typical of Autism.*²⁶

A fifth misconception and a rather sad one is that there is a "normal" person locked inside the person with ASD, especially if that person is a child. "(The classically autistic) child is an icon. It is a beautiful and remote child. The impression of high intelligence can be strong, as is the impression that a normal child is locked inside. But, alas, this is an illusion. It fades as the autistic child grows up."²⁷ The reason this is a sad misconception is really twofold: 1) It always leads to disappointment. ASD is not something that anyone "recovers" from. We will explore how outward improvement can sometimes be made in social situations through acquired coping mechanisms, but the disorder has not left. The person with ASD is simply working that much

²² Albers et al. et al, 163

²³ Frith, 87-90

²⁴ DSM-V, 53

²⁵ Thomas Gumm, "Autism Spectrum Disorder: Please Accept Me, for God Made Me Different." (paper presented at the Puget Sound joint circuit meeting, Holy Trinity, Des Moines, Washington, November 14, 2011).

²⁶ Frith, 83

²⁷ Frith, 28

harder to interact in situations that he or she has always had difficulty in. 2) It takes a very harsh view of the person with ASD. It is fair to recognize that there is something different in people who have ASD and it is even okay to recognize that there is something wrong with the way they interact, but the small but important distinction this misconception makes is that it assumes there is something wrong with the person. It says in a certain way, “You’re not good enough because you have ASD. We’ll get it out of you and then you’ll be an acceptable person.” This is almost always not the intention of such a thought, but it is the implication and it needs to be watched out for.

Here is an interesting misconception: some get the idea that the diagnosis of Asperger’s Syndrome isn’t all that bad or isn’t as bad as a diagnosis of Autism. In the first place, as pointed out earlier, Asperger’s Syndrome is now considered part of ASD and will receive a diagnosis according to the new criteria as laid out in DSM-V. Some see the way people diagnosed with Asperger’s behave and see that it can be closer to societal norms than others with ASD. This is not however due to it being less serious of a disorder. It seems that the most likely reason this is sometimes observed is that in some with Asperger’s learning about societal norms can cover the more obvious signs of ASD.²⁸ There are even some who think of Asperger’s being a more desirable diagnosis than Autism because it is in the public mind often linked with genius.²⁹ This should not be the case, however. As pointed out in the section on the misconception that all people with ASD are savants, it is unfair to expect genius from a person with ASD. It can be the case that a person with Asperger’s will have an elevated IQ. But that should not be expected.

The final misconception about ASD is possibly the most well-known misconception: that outside factors, especially vaccines, are contributing in a major way to the apparent rise of Autism. It is a fact that from 1990 to 2008 there was an increase in the diagnosis of Autism of 172 percent.³⁰ As will be discussed more fully in section 1c, ASD seems to be present from before birth, even though the symptoms may not show up until later. Frith says, “It is very unlikely that Autism is caused by some adverse environmental event after birth...the abnormalities that can be detected in the nerve cells of autistic brains date from well before birth.”³¹

²⁸ Frith, 33

²⁹ Frith, 35

³⁰ Frith, 39

³¹ Frith, 44

There are a few reasons that vaccines are singled out as a cause of ASD. There has always been a fear of vaccines; the idea of exposing a child to a serious disease is a hard one to swallow.³² This fear was exacerbated with the addition to the vaccine regimen of a “triple vaccine.” “Three at once?” some thought, “That’s simply too much.” So when the MMR vaccine came out it was an easy target. Parents seemed to have confirmation of their fears when their children who had previously seemed okay began developing symptoms of ASD after having vaccines. Uta Frith reports on the resulting studies based on these very understandable fears:

*Could the triple vaccination (MMR) be linked to the increase in Autism? It was pursued vigorously in a number of studies worldwide. Almost unanimously these studies came up with a resoundingly negative answer. Study after study demonstrated that the increase in Autism started long before triple vaccination was introduced. The last nail in the coffin was that the withdrawal of MMR in Japan did nothing to stop the rise of cases of ASD.*³³

The other concern parents had about vaccines was that it was the mercury in them that was entering the bloodstream and causing the Autism. Frith reports on this also:

*However researchers were able to rule out mercury poisoning as a cause of Autism, comparing children exposed to mercury with those who were not. Furthermore, the number of Autism cases continued to increase in California after Thimerosal (a derivative of mercury) was removed from vaccines.*³⁴

Thus, careful scientific studies have shown that ASD is not caused by vaccines nor the preservatives in them. What about those symptoms showing up after vaccinations? The time that symptoms of most ASD³⁵ appear in a childhood just happens to coincide with the age that children receive their vaccines: two years old.³⁶ It should be noted that this does not make it any easier for parents of children with ASD or for the children with ASD. It is a very difficult thing to hear and accept that your seemingly healthy child is not as healthy as you had been told and were expecting. ASD is a lifelong disorder and a life-changing disorder. It is also important to gently remind people that chasing falsehoods will not cure their child nor prevent it from happening to anyone else.

The final question to answer regarding this misconception then is, “what is causing this 172 percent increase?” Really, it makes perfect sense here that an increase in diagnoses would

³² This fear is also based in the lack of understanding that vaccines are not made using active viruses.

³³ Frith 45

³⁴ Frith, 45-46

³⁵ One of the things that can differentiate Asperger’s from classic Autism is that Asperger’s has a curious tendency to show up later in life, about 8 years old.

³⁶ Frith, 14

happen over the last 20 years. There has been an incredible increase in awareness of ASD in that timeframe. When that is coupled with the changing and more well-defined criteria for diagnosing ASD it only makes sense that there would be a dramatic increase in diagnoses of ASD.³⁷ The trick going forward then will be to distinguish between on the one hand, increases in ASD caused by this increased awareness and on the other hand, a possible true increase in cases of ASD. With ASD only being recognized as its own entity for slightly over 100 years, it is going to be hard to say how common the disorder was in the past. Therefore, it may take some number of years to create a baseline of occurrences to measure increases from. In the meantime, there is no reason for alarm at numbers like 172 percent. That is a big number; but it is not a sign of an epidemic, as the media likes to portray. There may well be an increase in the number of true cases, but there may not be. There simply is not a strong enough base of evidence to draw very firm conclusions from yet.

In this section I presented several defenses of the behavior of people with ASD to help bring understanding as to why they might do some of the things they do. This type of talk may bring about the impression that I am positing that every action by a person with ASD is defensible and there is no sin in a person with ASD. Of course that is completely false. There is the danger to consider all people with ASD as “lovable eccentrics” like Raymond in “Rain Man.” Even a secular writer like Frith points out, “Rain Man is an ambassador of Autism. But not all individuals with ASD are loveable eccentrics with amazing gifts. Far from it. Many are difficult to live with and many have additional problems.”³⁸ It is important as you interact with a person with ASD to realize that this is a sinful human just like any other and this person needs both Law and Gospel. There will be some different ways of communicating those truths with this person, but sin should not be excused because of ASD. That said, it is also of utmost importance to not go overboard here and forget that there is a disorder and not all uncouth behavior is intentional. As always, the distinction between Law and Gospel is a tight line to walk, but important nonetheless.

³⁷ Frith, 51

³⁸ Frith, 29

C: Behaviors – What Autism Spectrum Disorder Looks Like

It is good and helpful to protect yourself from stereotyping and over-generalizing a disorder like ASD by being aware of what some of the misconceptions of the disorder are; but the best way to protect yourself is to be familiar with what the disorder actually looks like in the first place. To get familiar with the disorder it will be good to start with some definitions. First, “Autism is classified as a neurodevelopmental disorder”³⁹ and a neurodevelopmental disorder is “a group of conditions with onset in the developmental period.”⁴⁰ There are four things professionals will look for when diagnosing someone with ASD. 1) “Persistent impairment in reciprocal social communication and interaction” 2) “Restricted repetitive patterns of behaviors, interests, or activities” 3) “Symptoms present from childhood” and 4) “[Symptoms] limit or impair everyday functioning.”⁴¹ They will also be careful to note that “disturbances are not explained by intellectual disability or developmental delay.”⁴²

Perhaps you have met someone with ASD and that person had other problems beyond ASD. There are certain other things that ASD may come together with. They include, “1) Intellectual impairment, 2) Language impairment, 3) Medical, genetic, or environmental factors, 4) Another neurodevelopmental, mental, or behavioral disorder.”⁴³ These other factors can make the problems that come with ASD itself that much more difficult to handle. You can teach a person with an average or above average IQ tricks to get around some of the symptoms of their ASD. That’s not so easy to do when the person also has intellectual impairment.

While there are certain symptoms to look out for, there is no specific group of symptoms that a person with ASD will exhibit. It may be a few choice symptoms that the person exhibits. For another person there may be many symptoms present that manifest themselves completely differently. Remember, *if you’ve met one person with Autism, you’ve met one person with Autism*. It is also important to understand that the symptoms may change or disappear over time as the person with ASD learns how to cope with the social world.⁴⁴

Some other things to know about ASD are 1) that the symptoms are usually recognized between 12 and 24 months of age; 2) ASD is not degenerative, that is, the symptoms can be

³⁹ DSM-V, 31

⁴⁰ DSM-V, 31 The developmental period is childhood through adolescence.

⁴¹ DSM-V, 53

⁴² DSM-V, 51

⁴³ DSM-V, 51

⁴⁴ DSM-V, 31

reduced by learning and compensation; 3) there is still very little known about old age and ASD; and finally, 4) there are four times as many males diagnosed with ASD as females.⁴⁵

Social Understanding and Reciprocal Interaction⁴⁶

Once you start interacting with a person with ASD it will often become apparent quickly what the biggest thing they have difficulty with tends to be: social understanding and interaction. “The first core feature of ASD concerns reciprocal social interaction. It is not enough to be a loner, to behave embarrassingly, or to be clumsy in social situations. The difficulty reveals itself most acutely in peer interactions. At young ages, this means other children - not adults.”⁴⁷ “Any reasonable person can understand what it must be like to be in a situation that is ambiguous, unpredictable, replete with buzzing confusion, and fearful. This is the social world of Autism.”⁴⁸ It is easy to become impatient, annoyed, or bothered in other ways when trying to communicate with a person with ASD. Try to keep in mind what that person is going through to communicate with you, even if it looks very “bad.” Uta Frith speaks of a teenager named David and says,

*[David] has obvious difficulties in communicating with other people who don't know him well. With those who do know him, he communicates entirely on his own terms. He makes no concessions to their wishes or interests and cannot take onboard another person's point of view. In this way David is indifferent to the social world and continues to live in a world of his own.*⁴⁹

Notice that she says, “he cannot take onboard another person’s point of view.” That is just it: these behaviors will not be things that are done out of rudeness or indifference, though they may seem that way. People with ASD simply have minds that do not function in a social way.

At the base of this confusing type of behavior is that people with ASD seem to not have a “social sense.” This is a somewhat unique thing among disabilities. “While blind and deaf children can still receive and respond to social signals through a special sense, autistic children don't have this sense.”⁵⁰ Being unable to communicate in a normal fashion just makes things more difficult in trying to come to solutions.

⁴⁵ DSM-V, 56-57

⁴⁶ Frith, 9

⁴⁷ Frith, 9

⁴⁸ Albers et al., 165

⁴⁹ Frith, 6

⁵⁰ Frith, 3

The difficulty in social interaction goes beyond being able to understand normal forms of social communication. It seems to go down to the way emotions are understood and processed. This does not by any means mean that people with ASD have no feelings. Pastor Gumm wrote, “I always thought that persons with ASD had limited feelings. I was told [in a meeting with a group of people diagnosed with Asperger’s] that, on the contrary, they have super-strong feelings that cannot be expressed in words.”⁵¹ But with this different way that emotions work you may run into situations like this:

*One of the recurrent themes in descriptions of social impairments is the lack of emotional resonance...Angela, the wife of Andrew, a man with Asperger syndrome, was extremely distressed when her father died. Andrew showed no sympathy and talked loudly and disparagingly about his father-in-law, saying it was his own fault that he had cancer, since he smoked. He never comforted Angela but seemed annoyed that she did not carry on with her usual routine. Ironically, Andrew is very aware of other people's suffering in an abstract sense. He always gives generously to a charity in Africa.*⁵²

It was not that Andrew was incapable of emotion nor was it that he did not love his wife. In most situations this would very clearly be a very unloving thing to do. In Andrew’s case however he simply could not fathom that his behavior would be causing his wife distress. As is pointed out, he was surprised and annoyed that Angela’s father’s death had affected Angela. He did not have the brain function that would make him understand that Angela would have a reaction to this event. Nor was he able to understand that his actions would have a negative impact on Angela either.⁵³ Frith puts it this way,

*Imagine the way we interact with a cash machine, and then imagine how we interact with another person. An autistic person would not see much difference between the two situations...We always probe how much our conversation partner has understood, how much he or she has been persuaded by us. We would not do this when faced with a machine.*⁵⁴

Some of the symptoms DSM-V points to in this category of ASD symptoms:

Deficits in nonverbal communication

1) *Poorly (used) non-verbal communication*

⁵¹ Gumm, “Autism Spectrum Disorder: Please Accept Me, for God Made Me Different.”

⁵² Frith, 79

⁵³ This seems like a good time to point out that there can be teaching of people with ASD to help them better understand these types of situations and thus improve their behavior. This will be addressed in Section 5: Solutions.

⁵⁴ Frith, 81

- 2) *Abnormalities in eye contact, body language, or deficits in understanding and use of gestures*
- 3) *Total lack of facial expression and nonverbal communication*⁵⁵

Deficits in developing, maintaining, and understanding relationships

- 1) *Difficulties adjusting behavior to suit various social contexts*
- 2) *Difficulties in sharing imaginative play or making friends*
- 3) *Absence of interest in peers*⁵⁶

“Young children may show little to no initiation of social interaction and no sharing of emotions.”⁵⁷ Early (between 12 months and 24 months) non-verbal indicators regarding communication that ASD may be present:

- 1) *Lack of pointing*
- 2) *Lack of showing*
- 3) *Lack of bringing objects*
- 4) *Lack of following gaze.*⁵⁸

Beyond deficits in non-verbal communicative behavior DSM-V points out deficits in relationships that are often indicators of ASD:

In young children:

- 1) *Absent, reduced, or atypical social interest*
- 2) *Rejection of others*
- 3) *Passivity*
- 4) *Inappropriate approaches that may seem aggressive or disruptive*⁵⁹

Among older individuals:

- 1) *Difficulty distinguishing between social contexts (such as casual behavior while at work)*
- 2) *A preference for solitary activities or time spent with younger or older individuals*
- 3) *A desire to establish friendships without entirely understanding the concept of friendship (One-sided friendships, friendship based solely on shared interests)*⁶⁰

⁵⁵ DSM-V, 50

⁵⁶ DSM-V, 50

⁵⁷ DSM-V, 53

⁵⁸ DSM-V, 54

⁵⁹ DSM-V, 54

⁶⁰ DSM-V, 54

Use of Language⁶¹

Connected to the problems people with ASD have communicating socially are problems they may have communicating using language. Just as a person with ASD may not be able to consider your interests and desires as you communicate with him or her, that person is also unable to understand when you are not being completely direct with him or her. Making jokes, using sarcasm, irony, or euphemisms are completely lost on people with ASD. They are not able to pick up the signals that the words you are using are not the words you mean.⁶² So saying something as simple as, “You really hit a home run on that test” will be supremely confusing because the person with ASD will be thinking, “I wasn’t playing baseball at all.” Now imagine that the person is trying to figure out why you were talking about baseball while he or she was thinking about a written exam as you move the conversation onto another topic. You ask the person a question and he or she didn’t hear the question. To you, that person seems like he or she doesn’t care for what you’ve said when really it is nothing like that. You can see why that becomes a problem for the person with ASD.

Some of the symptoms DSM-V points to in this category of ASD symptoms:

Deficits in social-emotional reciprocity:

- 1) *Abnormal social approach*
- 2) *Failure in normal back and forth conversation*
- 3) *Reduced sharing of interests, emotions, or affection*
- 4) *Failure to initiate or respond to social interactions.*

Common language deficits:

- 1) *A range from total lack of speech to language delays*
- 2) *Poor comprehension of speech*
- 3) *Echoed speech (echolalia)*
- 4) *Stilted or overly literal language*

Repetitive Behavior and Narrow Interests⁶³

The third category that you want to be familiar with when trying to understand behaviors of people with ASD is repetitive behavior and narrow interests. There is a tendency among people with ASD, especially children, to do things that are very repetitive or to become fixated on one thing and have no interest in anything else. “There is a strong resistance to change and an aversion to novelty. Doing the exact same thing, watching the same video, eating the same food,

⁶¹ Frith, 9

⁶² Frith, 9

⁶³ Frith, 11

day after day, is the kind of excessive pattern that is found in autistic children. It is often less noticeable in autistic adults.”⁶⁴ Susan Senator describes this type of behavior in her son Nat, as he learned to read. She writes,

He loved books that categorized things, like colors or food. Reading a book about colors, he would turn each thick cardboard page (it was a baby book) and point to each letter of each word: ‘O-R-A-N-G-E spells orange! R-E-D spells red!’ He read the entire book over and over, in a self-stimulatory manner...⁶⁵

There doesn’t seem to be a unifying aspect to what the repetition might be or what the unique interest may be. The other thing to realize is that these repetitions and interests can come and go over time.⁶⁶

Another way these interests may manifest themselves is in a certain type of food that the person with ASD will insist on eating, perhaps to the exclusion of all other food. Frith shares an example of this with yogurt:

Family life has always had to fit around David, not the other way round...At one stage he only ate yogurt and refused all other kinds of food. More often than not his mother has to give in to his urgent and repeated demands, which easily escalate into tantrums.⁶⁷

This category of behaviors may seem harmless or even cute to the outside observer, but they can be the most difficult area of symptoms for the people who live with the person with ASD. Even in this story about yogurt you will notice, “his mother *has* to give in.” It is not that she is a weak mother, unwilling to stand her ground. This type of thing simply escalates to the point where there is no other choice. With most children you can threaten to send them to bed with no supper and they will eventually become hungry and eat what is served. There are of course difficult days with children who do not have ASD, but with the child with ASD this kind of exaggerated difficulty can happen and when it happens it will be an every day, every meal situation.

The other thing that can happen is that outsiders see this type of behavior and don’t think it’s cute, but do judge the parents as bad parents because of this type of behavior. It is so important to understand that ASD is real and the behavior is not due to the parent’s lack of

⁶⁴ Frith, 11-12

⁶⁵ Susan Senator, *Making Peace With Autism: One Family’s Story of Struggle, Discovery, and Unexpected Gifts* (Boston: Trumpeter, 2006), 111-112.

⁶⁶ Frith, 40-41

⁶⁷ Frith, 5

parenting skills. The child is purely incapable of behaving differently once it gets to this point and nothing the parent is going to do in the moment is going to change that.

It is not necessarily only insistence on this sameness in one aspect of life, but it can and commonly does extend to all aspects of the person's life.⁶⁸ People with ASD very often want and will do much better with a strict structure and routine to their day and life.

Some of the symptoms DSM-V points to in this category of ASD symptoms:

Insistence on sameness, inflexible adherence to routines, ritualized patterns of behavior:

- 1) *Extreme distress at small changes*
- 2) *Difficulties with transitions*
- 3) *Rigid thinking patterns*
- 4) *Greeting rituals*
- 5) *A need to take the same route or eat the same food every day*

Highly restricted, fixated interests that are abnormal in intensity or focus:

- 1) *Strong attachment or preoccupation with abnormal objects*
- 2) *Excessively circumscribed or preservative interests*

Hyperactivity or hypoactivity to sensory input or unusual interest in sensory aspects of the environment:

- 1) *Indifference to pain or temperature*
- 2) *Adverse response to specific sounds or textures*
- 3) *Excessive smelling or touching of objects*
- 4) *Visual fascination with lights or movement*⁶⁹

This last area regarding the senses, which does not so much fall into the category of repetitive behavior, is present because there is not a better place to categorize it using the simplified three category approach in this paper. Nevertheless it is an important category to be aware of, since it has such an impact on worship life.

Darren C. White, for example, has described his perceptual experiences , 'I used to hate small shops because my eyesight used to make them look as if they were even smaller than they actually were ...I was rarely able to hear long sentences because my hearing distorted them. I was sometimes able to hear a word or two at the start ... and then the next lot of words sort of merged into one another and I could not make head or tail of it

⁶⁸ DSM-V, 50

⁶⁹ DSM-V, 50

*... I was so frightened of the vacuum cleaner, food mixer ... because they sounded about five times louder than they actually were. Life was terrifying ...*⁷⁰

As a symptom of ASD, sensory overstimulation has obvious implications in a worship service. There are bright lights, loud noises, and strong scents at times in worship. Given the way Mr. White describes his experience it's easy to imagine how hard it would be, especially for a child, to pay attention in worship. It can also be imagined why things such as excessive smelling or adverse responses to specific sounds or textures when coupled with the symptoms of social misunderstanding could cause difficulties for the child in a worship service. Can you imagine sitting in a pew when a child comes over and starts sniffing you excessively? It can't be said enough that in these situations it is of the utmost importance that the members of the congregation be flexible and understanding.

D: Causes of Autism Spectrum Disorder

This disorder is quite common, affecting one percent of Americans and thus impacting many more.⁷¹ It makes sense then that many want answers: how did this happen? In the section on misconceptions it was pointed out that while ASD appears around the time vaccines are administered the studies show that there simply is no connection between vaccination and ASD.

Currently there is no unified theory regarding the cause of ASD, there are too many symptoms and options for those studying the disorder to have yet come up with something conclusive.⁷² This does not mean that there is nothing that can be said about the causes of ASD. There are four main ideas about where the origins of ASD in the mind are.

When and where does ASD start? One of the biggest reasons that vaccines can be ruled out as a cause is that ASD's origins are usually attributed to being present before or around the time of birth.

There are a myriad of... potential causes that pertain mainly to noxious effects on fetal development in the intrauterine environment. These would include maternal rubella infections, medications taken during pregnancy, such as thalidomide, and circulating testosterone that can be a neurotoxin. Perinatal insults during and shortly after birth may

⁷⁰ Liz O'Brien, "Connecting with RE: An Approach to Religious Education for Children with Autism and/or Severe Developmental Disabilities," *Support for Learning* 19, no. 3 (August 2004): 133, accessed November 21, 2014, <http://search.ebscohost.com/login.aspx?direct=true&db=psych&AN=2004-17287-006&site=ehost-live>.

⁷¹ DSM-V, 55

⁷² Frith, 105

*have a causal role; for instance, fetal distress, emergency caesarean section, and labor induction.*⁷³

Frith is in agreement with these observations. She says, “It is very unlikely that Autism is caused by some adverse environmental event after birth...the abnormalities that can be detected in the nerve cells of autistic brains date from well before birth.”⁷⁴

So most cases of ASD can be shown to be from before birth and there is a possibility that deserves more research that some outside influences can have an impact in the womb or around the time of birth. An easy hypothesis to come to given these observations would be that there is a genetic component of ASD. Researchers looked into this very idea. Here is what was discovered with twin studies:

*The possible causes of Autism are many and varied. There is certainly a genetic contribution. Twin studies indicate a 60 percent concordance rate for monozygotic (identical) twins; that is, if one twin is diagnosed with Autism, there is a 60 percent chance that the identical twin will also receive the diagnosis.*⁷⁵

Given this clear genetic connection the assessment, “Hardly any other mental disorder is so highly genetic”⁷⁶ has obvious merit. You would think then that it would be easy to know from birth that a child has ASD. This, sadly, is not the case. At least 30 percent of children with ASD experience what is called, “regressive development.”⁷⁷ Regressive development is when a child who is developing as expected under normal circumstances begins to backtrack, developing the defining characteristics of ASD. So a child who may have at one time seemed to be socially interested will lose all interest in social interaction. This is sad because it is a devastating thing for the parents to go through. In their mind their child was completely healthy and then he or she began behaving differently.

The four ideas previously mentioned are 1) Theory of Mind, 2) Weak Central Coherence, 3) Mirror Systems, and 4) Executive Function. These ideas won’t provide an answer to what the cause of ASD is, but they will help to understand what different things are happening in the minds of individuals with ASD and if correct may help guide researchers into finding what the real cause of ASD is.

⁷³ Albers et al., 163

⁷⁴ Frith, 44

⁷⁵ Albers et al., 163

⁷⁶ Frith, 55

⁷⁷ Frith, 15

Theory of Mind

“*Theory of Mind*. This refers to the cognitive processes that provide the intellectual underpinning for empathy, the capacity vicariously to “feel” the emotions of another, to understand the motives and desires of a fellow human being.”⁷⁸ Uta Frith calls this, “mind reading”⁷⁹ and she’s right. No, it’s not the ability to get inside someone else’s head and to magically learn what he or she is thinking. Instead it’s the ability to assess a situation and imagine how the other person must be thinking about the situation. It’s realizing that other people even have a separate perspective of a situation from your own. She says,

*“The brain has a device that tells you where you are in relation to other people. We just know that people or characters in a story have wishes, feelings, and beliefs and most of the time we know pretty exactly what they are; most of us are born to read minds. Christopher [a character in a story who has ASD] can’t read minds.”*⁸⁰

There is a famous experiment that was conducted and has been repeated several times to demonstrate this aspect of thinking, this “sense.” It applies to people with ASD. It also applies to children who have not yet reached a certain stage of development.

The first ever test of the big idea (Theory of Mind) ...goes like this: Sally has a basket, and Anne has a box. Sally has a marble and puts it inside her basket. Then she goes to play outside. While Sally is away, naughty Anne takes the marble from the basket and puts it inside her own box. Now, it is time for Sally to come back. She wants to play with her marble. Where will she look for her marble? Most children, by the time they are 5 years old, can answer this question with great confidence. Sally will look for the marble in the basket, because that is where she believes it is. Her belief is now false; we know where the marble really is, but Sally does not know this.

*In contrast, even very clever children with Autism find the Sally-Anne test very hard. They tend to say that Sally will look where the marble really is. They do not take into account Sally's now outdated belief. They will eventually learn what is going on, but it takes them longer than normal developing children, and what they learn is something different from the easy and automatic grasp of the situation. In Autism mentalizing never seems to be effortless and automatic.*⁸¹

So the theory of mind and the discovery of the way people with ASD tend to handle tests regarding this brain function shows that part of ASD has to do with a failure in this area of the

⁷⁸ Albers et al., 161

⁷⁹ Frith, 65

⁸⁰ Frith, 67

⁸¹ Frith, 67-68

brain. It helps to explain why people with ASD would do something like not understand why it would be inappropriate to start sniffing something loudly while in church. The problem with only exploring this avenue to find a cause for ASD is that it ignores the deficits in the emotional aspects of communication.⁸²

Weak Central Coherence

Weak central coherence. It has been found consistently that individuals with Autism show interest in the concrete, the particulars, and not the whole... The world outside the autistic individual is like a series of still photographs swirling by one by one that are never fused together into a "motion picture"; the autistic person is interested in the details but not the whole, complete configuration.⁸³

Weak central coherence is an interesting aspect of this big puzzle. There may be times that it would be supremely beneficial. Weak central coherence is essentially the inability to take in all the parts and make a whole. While most of the time you do want to see a whole when you look at a situation, there are times when being better able to observe all the parts without trying to put your own interpretation of a whole on the situation would be of great benefit, like finding Waldo in a Where's Waldo book.⁸⁴ Of course, this does not always play out as an advantage for a person with ASD.

One idea was that autistic children cared for the possibly meaningless elements of a sentence or a picture, but not for the meaning of the whole sentence or the whole picture. If so, this was a completely different way of processing information. Could this processing style also lead to a different kind of intelligence? Could it explain special talents? These questions led to the theory of weak central coherence.⁸⁵

While weak central coherence may help you when memorizing numbers, finding Waldo, or putting a puzzle together, it can become a real problem when you are supposed to find the meaning behind a set of individual facts.

This idea tries to meld together the sometimes incredible things observed in people with ASD with the contextual deficits that are sometimes observed in people with ASD. There is a problem here too though: not all people with ASD suffer from weak central coherence.⁸⁶ This does not make the idea worthless however. It is likely that weak central coherence is related in

⁸² Frith, 72

⁸³ Albers et al., 161

⁸⁴ Frith, 88

⁸⁵ Frith, 88

⁸⁶ Frith, 90

some way to the ultimate cause of ASD, but it does not seem to be best route to discovering what that cause is.

Mirror Systems

“When we observe others performing an action our brain's mirror system is automatically active so that we are ready to perform the action ourselves. This is very useful because it allows us to understand other people's actions in a very different way.”⁸⁷ A great example of something that may be associated with mirror systems is yawning. It has been observed that when one person yawns, others around that person tend to replicate that action and yawn too. Children with ASD do not follow this pattern as much as children without ASD.⁸⁸

*Intentions and feelings are usually accompanied by movements in the face and body. Further, does a fault in the mirror system of the brain explain a lack of empathy? Empathy is often defined as a way of unconsciously copying the feelings of another person. Could a fault in this mechanism explain many of the social difficulties in Autism?*⁸⁹

Mirror systems become relevant in the discussion of the causes of ASD because emotions and empathy specifically seem to be related to this function of the brain. If you don't have the function that causes you to automatically copy other people physically then perhaps it will be harder for you to get a copy of their emotions as well.

As with all the ideas, this idea is not without its weaknesses. First of all, although the idea sounds very good, there is still very little evidence that these systems actually exist.⁹⁰ That does not mean it does not exist, but there does need to be more research done to figure out what is actually happening. Another thing working against this idea is that some of the predictions researchers have made about how this should play out in people with ASD have not stood up. For example, you would expect that people with ASD would be poorer at imitating other people's actions. The research shows that this is not the case.⁹¹

So the current idea of mirror systems may be flawed, but there does seem to be something there. “There is something amiss in autistic children's ability to imitate. There is also something amiss with their ability to inhibit imitation. This is seen, for instance, in the tendency

⁸⁷ Frith, 77

⁸⁸ Frith, 80

⁸⁹ Frith, 77

⁹⁰ Frith, 77

⁹¹ Frith, 77

to echo speech, a classic feature of Autism.”⁹² Hopefully with further research this idea will become better understood and will be a stepping stool on the way to understanding what the cause of ASD is.

Executive Function

*Executive functions. These are higher mental operations that facilitate adjustment and adaptation in life. They include the rational control of impulses (response inhibition), planning and goal setting, working memory (e.g., the ability to retrieve memories that will facilitate adjustment in a given situation), and attention including the shifting of attentional focus, concentration, and vigilance.*⁹³

The idea of poor executive function means that one has failures in inhibition and also can get stuck on certain things. The frontal lobes of the brain are where these aspects of thinking occur and so it makes sense to expect there to be a problem there.⁹⁴ This idea explains nicely the problems people with ASD have in things like stopping themselves from doing something, even though they have been told multiple times it is wrong. It also explains at the same time why people with ASD can have such narrow interests. This would be the “getting stuck” part; an example of getting stuck is the young man who would only eat yogurt.

It seems that in people who have ASD there is a problem in the frontal lobes; and researchers widely accept the idea that there are problems with executive function. What is interesting and unexpected is that observations of brain activity in people with ASD indicate that there does not seem to be any physical or other discernible problem with their frontal lobes. This does not disprove the idea of executive function, however. There could be a failure in another part of the brain that affects these apparent frontal lobe failures, but this would not show up in scans of the activity of the frontal lobes, rather there would have to be further testing and scanning done in those other areas of the brain. There is another concern however: that the idea of executive function is too broad and may be a core feature of all neurodevelopmental disorders.⁹⁵

All four of the ideas covered here have positives and negatives associated with them. It deserves to be said again that researchers still do not have a unified theory on the cause of ASD and there are still many unanswered questions. That does not mean there has not been progress

⁹² Frith, 78

⁹³ Albers et al., 161

⁹⁴ Frith, 97

⁹⁵ Frith, 98

made; there has been. However, you are going to be disappointed if you want solid answers about what causes this condition.

E: The Spectrum

Autism *Spectrum* Disorder – this is what the condition is now called. Why *spectrum*? “*Spectrum* refers to a range or continuum and was first referenced in what is now termed ‘Asperger Syndrome.’ The spectrum was a dimension from being odd but socially interacting on one end (Asperger Syndrome) to complete social aloofness on the other.”⁹⁶ The word spectrum is used because there are levels of severity and a range of symptoms involved in this disorder. If you’ve met one person with Autism, you’ve met one person with Autism. There are certain things you will hear when someone talks about ASD. You will hear, “high function,” “low functioning,” “Asperger’s,” and more. DSM-V has lumped many of the things previously considered separate into one category “Autism Spectrum Disorder” with the intention of offering more accurate diagnoses.⁹⁷

There was even recently confusion about what the word spectrum referred to.⁹⁸ Was it severity of symptoms? Was it the number of symptoms? Was it the ability to overcome symptoms? DSM-V tries to clear this up by narrowing the idea to severity levels. There are three levels: Level 1 – Requiring Support; Level 2 – Requiring Substantial Support; Level 3 – Requiring Very Substantial Support.⁹⁹

This talk about the spectrum means that “there are no unique sets of behaviors, which will unequivocally identify Autism. Two children whose Autism is caused by the same biological factor may nevertheless appear different from each other.”¹⁰⁰ Some people with ASD are going to have an easier time than others. It is more convenient to think about people with ASD who are high functioning, but that line of thinking is not helpful nor does it do any favors for those people who are low-functioning.

There are different titles given depending on where on the spectrum people fall. There is “high functioning,” which generally means that the person has an average or above average IQ. There is “low functioning,” which generally means the person has a lower IQ or is more self-

⁹⁶ Albers et al., 159

⁹⁷ DSM-V, 53

⁹⁸ Frith, 21

⁹⁹ DSM-V, 52 To see this table please turn to Appendix A

¹⁰⁰ Frith, 107

absorbed. You will also likely hear about “Asperger’s Syndrome,” which I have already mentioned several times in this paper. Generally speaking, Asperger’s Syndrome is very similar to high functioning Autism, except its symptoms curiously appear later, around the age of eight instead of one or two years old.¹⁰¹

The most important thing to remember about the spectrum is that you are going to have to be flexible when meeting a person with ASD and you should not expect to be able to apply your previous experiences with a person with ASD to this new person you are meeting. You will certainly see similarities, but the way you handle the symptoms in the new person may be different in almost every way.

Section 2: Worship Difficulties

This paper exists because there are difficulties for children with ASD in the worship service. People leave churches because of these difficulties. In fact, almost one third of parents of children with ASD in America have changed churches because of the problems they’ve encountered.

*Almost one third of parents reported having changed their place of worship because their child had not been included or welcomed; almost half had refrained from participating; more than half had kept their sons or daughters from participating in a religious activity because of a lack of support; and more than half had been expected to stay with their sons or daughters in order for participation to occur. Finally, more than half of parents reported they had never been asked about the best way to include their sons or daughters in religious activities.*¹⁰²

Children with ASD have a harder time than grown people with ASD coping with their disorder, but those difficulties can be overcome with education and coping devices learned.¹⁰³ Finally it is important to keep in mind that children with ASD grow into adults with ASD. They may be able to move out one day and live fine on their own or they may have to live their entire life with help and supervision, depending on where on the spectrum they fall. In the worship life of children with ASD this means that the congregation must also learn how to cope with having a

¹⁰¹ Frith, 33

¹⁰² Jones, Melinda, and Belva Collins, and Erik Carter. “Congregational Participation and Supports for Children and Adults with Disabilities: Parent Perceptions,” *Intellectual and Developmental Disabilities* 51, no. 1 (December 2012): 55, accessed November 21, 2014, <http://search.ebscohost.com/login.aspx?direct=true&db=psych&AN=2013-04505-004&site=ehost-live>.

¹⁰³ Frith, 12

person with ASD in their congregation, and this will affect everyone in the congregation, even beyond the childhood of that person.

'Autism never affects one person alone; it involves the whole family and the whole community' (Walsh et al. 2008. 12). This is also true in the faith community. Having a child with Autism in the faith community not only affects parents and siblings of the child but each member and leader of the faith community.

The first group of difficulties in worship life to look at really has nothing to do with the child with ASD and everything to do with us, the people worshipping alongside the person with ASD. Here is the kind of "horror story" mentioned before:

Our family began attending mass at the beginning of July 2006. We introduced ourselves to the ushers and lectors at mass, our pastor and the director of religious education for the parish. We especially took the time to introduce our children, Eoin and Colin. Colin, our 4-year-old, has Autism. Our priest and the religious education director made us feel very welcome, in every way, and asked us if there was anything at all they could do to assist with making Colin feel comfortable and to please let us know.

Unfortunately, not all of the parishioners were as welcoming as the parish staff. We were attending an 11:30 am mass and sat in the back, like we usually do, in case we needed to give Colin a break. He was pretty quiet, however, drank his juice, ate cheerios and played with his matchbox cars. He did move around a bit and was a little restless, but not overly distracting to any one around us. Or so we thought! During the mass when it came time for the sign of peace greeting, I reached out my hand in a sign of peace and the woman sitting next to me refused to shake my hand. She said while pointing at our son Colin – after I had offered "Peace be with you" – "I don't think so..." "He doesn't belong here – he is not ready for mass." I explained he had Autism and said I was sorry she felt that way. She replied, "I know all about you." I told her, "God made him the way he is" and she said, "Don't give me that." I then said to her, "Shame on you." At that point we received communion and rather than return to my seat next to that woman, I stayed at the back of the church with Colin. When mass was over, she pursued an exchange of words with my husband.

She explained she was a teacher for forty years, and in her judgment Colin did not belong at mass with us – he wasn't ready. She recommended we sit in the "cry room." I explained that did not work for our family. She clearly did not want to compromise. My husband asked if she could display some patience and tolerance as a fellow Christian that that was all we wanted from her. She responded, "That is not what you want, you want my pity!" At that point I asked my husband to leave and I told her that we would like to take up our concerns with the pastor for him to decide.¹⁰⁴

¹⁰⁴ Walsh, Mary Beth, Alice F. Walsh, and William C. Gaventa, eds. May, 2008. "Autism and Faith: A Journey into Community." 40, <http://rwjms.umdj.edu/boggscenter/products/documents/AutismandFaith.pdf>.

Lest you think this is a one-time occurrence that happened in a Catholic service and would never happen at your congregation, remember again that one third of all families with children with ASD have changed congregations. This family did not even change congregations after this! You can be sure that more than one third of families with children with ASD have experienced this type of thing at some point in time. The studies show that many people in Christian churches simply do not know how to handle having a child with ASD in the sanctuary during worship.¹⁰⁵

Two more stories about experiences families had in churches:

A family had been members of a certain congregation for many years. When their son with Autism became a teenager and grew to be about six feet tall, some members felt threatened by his physical size and odd behavior. Conversations between the pastor, members, and family became heated and polarized. The family continued to attend worship, and the members continued to complain. Finally, the congregation took out a restraining order on the mother and her son so they would be arrested if they attended worship.

Another mother wanted her son with Autism to be confirmed in the church where they were members. The priest in this large Catholic church told the mother the child would be too much work and they would not be able to accommodate him. She responded by immediately looking for a church that would confirm her son. She found a medium-sized Lutheran congregation where she and her son felt welcomed. This congregation had spent the last four years learning how to welcome and accept another child with Autism and his family.¹⁰⁶

So far three specific problems have been identified in stories. In the first story, disruptive behavior in the service caused a member to be rude and unwelcoming toward a new family. In the second story, the size of the child and his behavior caused members to make it illegal for this family to attend worship. Finally, in the third story, the priest refused to take the extra time necessary to train the boy with ASD. Clearly in each of these stories there was an issue that had to do with the behavior or difficulties of the child with ASD; but the reactions of the people in the congregations were completely inappropriate and not obeying the call to humility in Philippians 2:3 “Do nothing out of selfish ambition or vain conceit. Rather, in humility value others above yourselves.”

¹⁰⁵Poston, Denise, and Ann Turnbull, “The Role of Spirituality and Religion in Family Quality of Life for Families of Children with Disabilities,” *Education and Training in Developmental Disabilities* 39, no. 2 (June 2004): 103.

¹⁰⁶Albers et al., 165-166

One last story:

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

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.¹⁰⁷

Here is an example of a non-behavior related worship difficulty paired together with another congregation reacting inappropriately. This time the difficulty stemmed from the need of Daniel to think things through, a common aspect of people with Asperger’s. “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.”¹⁰⁸ This strong preference for physical evidence requires patience on the part of a congregation. It’s not that the person is incapable of having faith.

Now the stories shared here have all focused on mistakes made by the congregation and that is by design. There are certainly going to be times when families of children with ASD also create difficulties by being too inflexible themselves or combative or entitled. The point here however is that having a child with ASD is going to create a barrier for that child and his or her family in the worship service. Since the stories shared focus only on some general problems it would be good to list symptoms of ASD that have the potential to cause difficulties in worship:¹⁰⁹

- 1) Not adjusting to different social contexts
- 2) Poorly used non-verbal communication
- 3) Rejection of others
- 4) Disruptive approaches to communication
- 5) Preference for solitary activities

¹⁰⁷ Gumm, “Autism Spectrum Disorder: Please Accept Me, for God Made Me Different.”

¹⁰⁸ Gumm, “Autism Spectrum Disorder: Please Accept Me, for God Made Me Different.”

¹⁰⁹ You will notice these symptoms are taken from Section 1

- 6) Failure in conversation
- 7) Poor comprehension of speech
- 8) Echolalia
- 9) Difficulties with transitions
- 10) Ritualized greeting patterns
- 11) Extreme distress at small changes
- 12) Strong interest in abnormal objects
- 13) Adverse responses to specific sounds or textures
- 14) Excessive smelling or touching of objects
- 15) Extreme sensitivity to sensory experiences

This is only a small sampling of the range of symptoms that present difficulties for children with ASD. Not every person with ASD will experience difficulties from all of these potential symptoms; nor will they experience them to the same degree; nor will they experience them in the same way. Having a child with ASD in your congregation will take a great amount of flexibility on the part of everyone involved: child, parents, pastor, leaders, and congregants. However, with flexibility many of these difficulties can be worked around and provided for.

Section 3: Solutions to Worship Difficulties

“Autism is a developmental disorder. Development means change, and in Autism it usually means improvement...These improvements can all be expected when there is good education and support for the growing child and his or her family.”¹¹⁰ This quotation was aimed at the general life of individuals with ASD, but it also applies to worship life. Not only should the congregation be willing to help a child with ASD in his or her ability to worship comfortably, but with patience and education real growth can be made. Just because the child with ASD may present very severe difficulties it is important to remember that we are not cut off from that child completely.¹¹¹ A supportive environment for the person with ASD can make all the difference.¹¹²

There are five general categories that will be suggested to help children with ASD worship unhindered: 1) A welcoming attitude by the congregation 2) Getting to know the child and working with the parents to make a plan 3) Establish a routine for the child at worship 4) Train one or a few individuals specially to work with the child 5) Seek resources.

A Welcoming Attitude

¹¹⁰ Frith, 12

¹¹¹ Frith, 84

¹¹² Frith, 107

It may seem obvious, but far and away the most important thing and most cited thing that is helpful to children with ASD and their families in worship is for the congregation to have a welcoming attitude. “Overwhelmingly, parents rated a welcoming attitude toward people with disabilities as helpful (91.5%)”¹¹³ “Parents generally were not satisfied with the level of supports provided by faith communities, and they highly valued a welcoming and supportive attitude by the community.”¹¹⁴

What are the things parents are looking for the congregation to do to help them? This is clearly it: be welcoming.

*“Based on the families’ comments in this research, we suggest that families are looking for three things from their religious community: (a) **acceptance of their child**, (b) spiritual and emotional support for themselves, and (c) supports for their child during services so that both their child and themselves can have meaningful participation in religious activities.”*¹¹⁵

In congregations that are welcoming, “Several respondents spoke about how their child was accepted into all facets of the religious community. They described their church as a place of acceptance and unconditional love.”¹¹⁶ And this is exactly what God calls on us to do time after time in the Bible (Mt 28:16-20; 1 Pt 4:8-10; Mk 12:31; etc). Speaking the Word in truth is what changes hearts through the Holy Spirit and doing this is the first and most important step toward creating a church environment where people recognize this child with ASD as a fellow sinner whose sins Jesus paid for. Once that happens everything else becomes much easier and it becomes a matter of instructing people eager to accept someone else into the congregation.

Of course there are some specifics that can be done to help the family feel welcomed. Some of these will be covered in the other points but one that won’t be is to “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.”¹¹⁷

Some congregations have created teams to set up situations where the parents can get some alone time away from the children. Perhaps in a smaller congregation a few members who have experience with children with ASD or who would be willing to learn about it could

¹¹³ Melinda Jones et al., 54

¹¹⁴ Melinda Jones et al., 48

¹¹⁵ Denise Poston et al., 103-104

¹¹⁶ Denise Poston et al., 103

¹¹⁷ Gumm, “Autism Spectrum Disorder: Please Accept Me, for God Made Me Different.”

volunteer to babysit. In these congregations the parents of the children with ASD would in return volunteer their time and talents in other areas of the church's ministry.¹¹⁸

There are almost endless ways for a congregation to help make a family with a child with ASD feel welcome. The real trick is that the people make the extra effort needed and it doesn't even have to be a big gesture; but it does need to be understood that an extra effort is needed to make a family in this situation feel welcomed. The pastor and the leaders of the congregation can lead the way on this by going out of their own way to make the family feel welcomed and then arranging with other members to get this started.

Getting to Know the Child and Working With the Parents to Make a Plan

The rest of the ideas will be part of creating that welcoming environment just described. Some of the problems a child with ASD will have in worship may have to do with things in the worship environment that are stressful to him or her. Uta Frith says, "So the best possible practical advice for those who are in daily contact with an autistic person is often just this: try and find out what the stressors are and remove them."¹¹⁹ Of course to do this you are going to have to communicate with the parents of the child or even the child himself or herself. In fact, communicating with the child is going to be very important for a pastor.¹²⁰ Anyone in the congregation can "get to know the child with Autism by asking the child herself or her parents some of the following questions: What are her likes and dislikes? What are her favorite activities? What are the signs of stress? What is calming for her?"¹²¹

Once you have spoken with the family and asked what some of the things are that are stressful to the child, work to make the worship space accommodating to his or her needs. This may mean helping the parents find a special type of noise-reducing ear phones called "musician's ears," changing the lighting or finding a special place for the family to sit that does not have lighting that will be perceived as harsh by the child, creating a specific seating area designed for the child, or other measures.

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

¹¹⁸ Denise Poston et al., 104-105

¹¹⁹ Frith, 107

¹²⁰ See Appendix B for a set of questions that can be asked when first meeting with a family with a child with ASD

¹²¹ Albers et al., 170

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.¹²²

In the end it is going to depend on what the stressors to the child are and it is also going to depend on what is reasonable for your congregation to do. The encouragement here is to find something that works for the child. The hard truth of the matter may just be that changes will have to happen if this child is going to be able to worship and identifying what those changes are will vary from child to child. The good news is that with patience, compassion, and instruction these changes can be put into place. It all comes back to that attitude.

As the child grows there may even be ways that you can incorporate the child into worship. Yes, ASD causes difficulties, but it does not render the person with ASD talentless, lacking interests, or strip him or her of the ability or right to serve. “(Autism) affects adversely the social network of the brain but, in the absence of mental retardation, also renders cognitive strengths regarding curiosity about the physical world together with predispositions to know and construct systems.”¹²³ People with ASD may very well have talents and interests that no one else in your congregation will have and will be able to serve in ways that others can’t. Do not be afraid to have the child use his or her talents!

Establishing a Routine for the Child at Worship

“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.”¹²⁴

One of the most helpful things to reduce stress and breakdowns in behavior in children with ASD is to establish a routine that is regularly followed every day. This is what is used in schools for students with ASD.

Eric Schopler (1927-2006) created a center for the assessment and amelioration of behavioral difficulties associated with Autism and severe learning disabilities. His approach emphasizes a highly structured timetable and uses pictures in a concrete and at the same time imaginative way. It is known as TEACCH and has spread all over the world. You can see the typical visual aids, depicting a series of activities laid out in a clear timetable in almost all schools for autistic children, but also in centers for autistic

¹²² Gumm, “Autism Spectrum Disorder: Please Accept Me, for God Made Me Different.”

¹²³ Albers et al., 165

¹²⁴ Gumm, “Autism Spectrum Disorder: Please Accept Me, for God Made Me Different.”

*adults. The child or adult knows that they can always check their own timetable to know where they are in the course of the day and what to do next. This has an enormously reassuring effect and acts as a vital scaffold to organize work and leisure.*¹²⁵

This approach can be adopted to your worship. A very stressful thing for a person with ASD is to have a different liturgy every time he or she comes to church.

*Liturgies and rituals do not have to become stale, but they can become a forming influence in the lives of all the faithful. If the order of worship changes totally from one week to another, it may not only be stressful to the person with Autism, but other members also...One congregation had a child with Autism as a member, and any change in the order of worship was stressful for this child. When there was a change to the worship, someone from the congregation would contact the family a few days before worship to inform them of the change and to give them the new order of worship. This gave the family time to prepare the child for the coming worship service.*¹²⁶

This type of preparation is something that is very reasonable to implement. It takes effort on the part of the family, but they will be used to making preparations for going out of the house anyway. They will more than likely be extremely happy to do this as it will allow the child to have a much better experience. The other really good part of this is that it takes very little effort on the part of the congregation, yet allows them to be involved in creating that welcoming environment for the child and family.

Train One or a Few Individuals Specially to Work With the Child

If your congregation has someone with experience working with children with ASD already then count yourselves very blessed. Communicate with this person and allow them to offer suggestions for this new family. You may want this person to take the lead in working with the family in integrating into worship. You will also want those who lead worship to be in tune with what this person is saying and be prepared to be open to his or her suggestions.

Of course, it may not be reasonable to ask this person to add to their likely busy schedule to work with this child in your congregation. In that case perhaps this person could work with another to give some main pointers with being involved with the family. Maybe this other person teaches Sunday School to the child, is the one who calls about liturgy changes, or is the go between for the family and the people planning worship.

It is very likely that your congregation won't have a person who has been specially trained to work with children with ASD. If that is the case, it may be worth considering having

¹²⁵ Frith, 25

¹²⁶ Albers et al., 169-170

someone or a few people take the lead in learning about children with ASD. These would be the people you would want to do the previously suggested tasks among others. It would be convenient to have someone that other groups in the congregation could approach and ask if something is a good idea. Of course, the best people to ask in these situations will always be the parents themselves.

Seek Resources

There are all kinds of resources for teaching and accommodating children with ASD. There are significantly fewer resources dealing specifically with worship, but much of the other resources have crossover. Continue to educate yourself about ASD. Keep up with the latest techniques for dealing with children with ASD, as you are able.

Religious leaders can turn to several community resources. Local disability agencies, chapters of The Arc or other disability organizations usually have a community outreach program that provides information and awareness on general disability issues. These organizations may also be able to provide support to religious staff as they support specific children with disabilities. Oftentimes, the parents of children with disabilities are more than willing to share information about their child. Religious leaders can ask if parents would be willing to share information with the congregation at large or with specific people (e.g., teachers, nursery staff) who will be working with their children. Educators may be able to share some information on topics such as adapting curriculum, positive behavior support and social skills.¹²⁷

Within the WELS the group that you would look to contact is Jesus Cares Ministry. Their website is <http://www.tlha.org/jesus-cares-ministries/>.

¹²⁷ Denise Poston et al., 105

Conclusion

There is a very short history of Autism Spectrum Disorder. Only being recognized for 100 years means that there is still much research to be done. We do however know some things about ASD that were previously overlooked. The long list of abnormal behaviors and unexpected ways of thinking help us to be more accommodating to those who have this disorder.

ASD is a difficult disorder for someone to live with and it is awful that it interferes with the worship life of individuals with it. Thankfully there are things that congregations can do to help these children be able to participate in worship nearly unhindered. And thanks to parents who work hard for their children one of the biggest things a congregation can do to help really has no impact on them because it is what they are likely to do anyway: be welcoming.

There are other things congregations can do to help children with ASD and their families in the worship service. It is difficult if not impossible to come up with a comprehensive list of things to do though, because every child with ASD is going to be different. What works for one child will not work for another. The behaviors one child exhibits will not be the same as the behaviors another exhibits. The best way to deal with this is to be aware of the more general categories of behaviors children with ASD may partake in and be prepared to adjust to them.

The last behavioral piece of good news for children with ASD, their families, and their congregations is that improvement can be made with patience and careful instruction. ASD is a developmental disorder and thus learning can happen. It is more difficult when the child has other intellectual disabilities, but even then there is hope for improvement in terms of ASD behaviors.

Children with ASD are just that, *children* who happen to have a disorder. Jesus said, “Let the little children come to me, and do not hinder them, for the kingdom of heaven belongs to such as these.” (Mt 19:14) And that applies to children who have ASD. The sinful nature will have its moments where it brings us down to not being understanding and wanting to be selfish in worship and all areas of life. In those moments remember Hebrews 10:10, “we have been made holy through the sacrifice of the body of Jesus Christ once for all.” Jesus’ sacrifice bought salvation for this child as well as you and he or she needs to hear God’s Word and receive the sacraments just as much as any other sinner. Through Spirit-worked faith in Christ, this child will be in heaven with all of God’s people and see Jesus return to reign in his new heavens and earth.

TABLE 2 Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

¹²⁸ DSM- V, 52

Appendix B¹²⁹

Guidelines for Clergy and Religious Educators for Conversations with Parents

Present an overall attitude of openness and a desire to be supportive.

- 1) What are his/her special interests?
- 2) What are his/her special gifts?
- 3) Let the parent(s) know that in order to provide as positive an experience as possible, certain information will be helpful:
 - a) How would they describe his/her social relationships?
 - b) What methods of communication are used?
 - c) What have been effective learning strategies?
 - d) Are there any aggressive or inappropriate behaviors?
 - e) What are possible triggers of inappropriate behavior?
 - f) What is helpful for holding his/her attention?
 - g) Are they willing to share a copy of his/her IEP, or at least what the requirements of it are? (It is important to recognize and respect the confidential nature of such a document. Again, let them know that the reason for requesting it is to improve the quality of the experience for their child.)
 - h) Does she/he have any dietary or environmental issues?
 - i) Does she/he have any medical issues you need to be aware of?

¹²⁹ Walsh et al., 23

Appendix C
Other Reading and Viewing Resources

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