

Embracing *the* Autism Spectrum



Finding Hope & Joy Navigating the
NeuroDiverse Family Journey

REV. DR. STEPHANIE C. HOLMES
and **REV. DAN HOLMES**
with **SYDNEY HOLMES & ERICA HOLMES**

Appendix and
Resource Guide

Appendix A: Autism and the Blended Family: Blending a Family on Hard Mode

Article and Interview with Ron Deal of Smart Stepfamilies and FamilyLife Blended.

A Single Parent Perspective by John Felageller (Joni & Friends (IL)).

Appendix B: Resources for Parents of Children and Teens on the Autism Spectrum & Resources for Marriages & Families

Classes and Courses through Dr. Holmes and Autism Spectrum Resources for Marriage & Family, LLC

Contact for Marriage and Family Coaches

Podcasts, Blogs and Resources from Christians on Autism or Autism Parenting

Exceptional Needs Today Magazine (Free subscription magazine)

Appendix C: Resources for Churches & Ministries

Training and Support Access through SOAR, Key Ministries, and Joni & Friends and for those in Georgia or the Southeast, Together We Care Conferences.

Appendix D: Articles and Blogs

Blogs and Article written or co-written by Dr. Stephanie Holmes and an interview with world renown autism researcher, Dr. Tony Attwood.

Appendix A

Autism and the Blended Family: Blending a Family on Hard Mode

Detours, Breakdowns and New Routes of the Journey

Ron L. Deal & Stephanie C. Holmes, initially published in *Autism Parenting Magazine*, June 2016 (Issue 48, page 29). Used with permission. Also used with permission from co-author Ron L. Deal and Smart Stepfamilies.

About a decade ago, “research” that struck fear in the hearts of many families with a child on the autism spectrum, exaggerated the statistic that 80% of marriages with a child on the spectrum will end up in divorce. While this research has been debunked, indeed, it is true that family systems where there are more complexities and challenges, such as autism will have additional marriage strain. The divorce rate among neurodiverse families over neurotypical families certainly is higher, but there is not adequate research that indicates how much higher. Anecdotally, in my counseling practice and in the practices of colleagues is an increasing number of families that are blending families where a child or spouse is on the autism spectrum. Ron Deal is a leading expert in Christian counseling in the field of blending or stepfamilies. I reached out to Ron to collaborate on an article on autism in the blending family. The first part of this chapter is a story based on actual issues but are not reflective of either counselor’s clientele.

Looking back, Carol, a mother with an AS/ASD (Autism Spectrum/Autism Spectrum Disorder) child, could easily describe how hard being a single parent was; she prayed for years for a loving husband to help her raise her ASD son and his N-T (neuro-typical) older sister. Now, remarried and trying to blend a stepfamily of six, she wonders if staying single would have served her children better. Rachel, Carol’s 12-year-old daughter and big sister to Andy, her 9-year-old ASD child, really liked Jerry at first; and she was glad to see her mom dating again. As the big sister in a single-parent home, Rachel had grown accustomed to helping mom care for Andy. She also worried about her mother, who was abandoned by Rachel’s father over conflicts in caring for Andy and who was essentially alone to provide financially for the family and manage the home. Jerry made her mom smile and laugh again; Rachel loved seeing that.

Eventually, however, the initial lift brought to Carol and the home fell prey to the task of integrating two families. Jerry brought two children to the marriage: a 13-year-old daughter and 10-year-old son (both neuro-typical or N-T). He shares custody with his ex-wife and the kids split their time between the two homes. It turns out that Jerry and Carol did much of their dating while his kids were at their mom’s house, so no one quite anticipated the relationship between the kids would be once the wedding took place and everyone moved in together. Part-time “getting to know you” activity became a full-time clash of realities. Merging two families is nearly always stressful for stepfamilies; they are combining cultures, values, loss narratives, parenting styles, financial situations, and daily living preferences all while trying to

learn to love and trust after having been wounded and scarred by the past. In the best of situations, this naturally creates stress. Add a special needs child and parenting demands to the list and stress increases exponentially.

Jerry assumed that because his son, Tyler, and Andy were so close in age, they would enjoy each other and play well together. He wanted them to share a room, but Carol insisted that Andy keep his room to maintain continuity for Andy amid family change. Jerry, now Andy's stepdad, became aggravated that Andy gets "so many unfair privileges." But his frustration escalated to fear after about a year into the marriage when his son started dragging his feet about coming over for visitation. When Jerry asked Tyler why, he said he'd rather stay at his mom's than have to deal with Andy. Meanwhile, things between Carol and Rachel could have been better with Jerry's daughter, Jennifer. Stepmothers and stepdaughters commonly have tension while bonding, but Carol and Jennifer's relationship was complicated even more by Andy. And then there were the differences between girls. In caring for her brother over time, Rachel had matured beyond her years; Carol couldn't understand why Jennifer wasn't the same. Jennifer seemed self-absorbed in comparison. Needless to say, the two sides—mother and daughter vs. Jennifer—remained disconnected and struggled to enjoy each other.

Like salt in a wound, these stepfamily issues just added stress to the never-ending emotional, educational, and physical care of Andy. As before Carol hoped her ex-husband (Andy's father) would step in and help but he declined most of his visitation time and when he did take Andy and Rachel for the weekend, he refused to honor Carol's structure for their son. Andy would get out of sync and spread the distress on the rest of the family upon returning home. Carol was at a loss. She thought maybe she should have stayed single.

Finding Hope

In addition to renewing their spiritual values, Carol and Jerry will find hope for their family when they merge what they learn about healthy stepfamily living and effective ASD parenting. There must be growth on both sides and a stronger couple unity in managing their home, but in the meantime, they should expect stress and transition. A person on the autism spectrum (AS/ASD) has many routines. Sometimes, they can be rigid, will have a restrictive and/or intense passionate focus, struggle to connect interpersonally and emotionally, may have behavioral challenges, and usually does not respond well to change. Growing as a stepfamily involves a huge amount of change. It is no wonder, then, that many clinicians believe the divorce rate of ASD blended families to be higher than other stepfamilies. Couples must be proactive to avoid another family disruption by becoming proactive in managing their home and protecting their marriage.

Practical Help for ASD Stepfamilies

A thorough exploration of ASD stepfamily dynamics would require an entire book. However, below is some practical help for commonly reported dilemmas. For more on healthy stepfamily living read Ron's articles or books including *The Smart Stepfamily* and *The*

Smart Stepfamily Marriage. Ron and Stephanie have done 3 podcasts on this topic together as well through Neurodiverse Christian Couples and Family Life Blended's podcast.

Perspective for Stepparents

You knew when you stepped into the picture that caring for an ASD child meant carrying all the responsibilities and obligations of parenthood, however, you may not have fully understood what that meant until after the wedding; experiencing AS/ASD daily will undoubtedly open your eyes. It is okay to learn as you go; but learn you must. Keep an open mind, ask lots of questions, and make it your goal to unify your marriage around ASD matters. The protocols or needs of the child on the spectrum are not privileges or frivolous expenses. This may be hard for other children in the family to understand, but the parents can set the tone for acceptance and understanding of the autistic child's needs.

Let us add here that we applaud your willingness to give and love in this way. You are taking on a complex family system (and the autistic child may not fully understand or appreciate that) and are doing so by choice. This is a huge task, and we commend you for it.

In many (but not all) dissolved AS/ASD families one biological parent may have left the marriage and their parenting responsibilities to avoid stressors or responsibilities of having a special needs child. (Ironically, once you step in, they may now fight the structure or protocols you and your spouse put in place to support the AS/ASD child.) Don't feel obligated to make up for all their mistakes or fill all the gaps they left behind. Just be who you need to be and work in concert with your spouse (they are the expert on their ASD child) to determine your best role. Talk with your children and educate them about what is needed regarding structure in the home.

Here are some additional suggestions:

If you are still dating, move slowly toward marriage. Carol and Jerry inadvertently segregated their dating time and didn't allow all the children time to adjust to each other or the realities of an ASD parenting situation. This common mistake led to a huge blind spot that blindsided them after the wedding. Instead, take time to learn about AS/ASD while dating and share both what you're learning and experiencing with your kids (if you have them). As you increasingly consider marriage, be proactive to get all the children together (to the extent you can) in order to consider the family mix. What happens when they are together should carry a lot of weight. In other words, getting them together is not just a "play date", but it should be part of your decision whether you continue dating, marry, or go your separate ways. If you can't be a family, think long and hard about getting married.

Move slowly with transitions or significant changes. Getting married is a big transition. But for an ASD child, so is adding the stepparent's furniture to the home, or changing a Saturday afternoon routine to go see a new step-grandmother. Trust your spouse. Major and sudden changes may cause behavioral or emotional meltdowns and thus disruption to your family. AS/ASD persons can learn new transitions but move slowly.

Lower your bonding expectations. By definition AS/ASD persons have issues connecting relationally or define connection differently. This will be the same with you. Don't take it personally. Also, he or she may say socially inappropriate things when stressed like, "I don't like you", "I don't want you here", "I don't like those new kids—they are not my brothers and sisters", or "I want my dad", etc. These are expressions of difficulty with transition. Do not try to force yourself or your children into a relationship. Just focus on walking through the open doors you do have. As the child adjusts to the new normal and learns to trust you, (s)he will let you know when the door opens wider.

Connect with intentionality. A great way to bond with the AS/ASD child is through their passionate interests. For example, if they are into weather and weather patterns, learn about that and try to converse or do activities around that topic. Passionate interests are good access points for building relationships.

Learn Tolerance and Grow in Patience and Understanding. Learn why the AS/ASD child behaves the way they do. Understanding that their brain is not neurologically wired the same as other NT kids is vital. Learn all you can about their cognitive capacity and how you can work within it. While individuals on the autism spectrum are usually said to have differences in theory of mind and struggle with empathy, there is also a double empathy problem according to researchers. Double empathy is the inability for the NT person to understand the individual who is on the spectrum and show reciprocal empathy.

Bridge the Gaps in Your Marriage and Parenting

In the book *The Smart Stepmom*, Laura Petherbridge and Ron outline how children respond differently to biological parents and stepparents in blended families. Even when there isn't an AS/ASD child in the home, the contrast is striking. For example, when biological parents make a mistake, their children are quick to offer them forgiveness; stepparents receive quick judgement and children are easily angered at them. Biological parents are granted "insider status", get automatic love, approval, and trust, and are considered moral authorities. Stepchildren are deciding if and how much to love, approve of, trust, and listen to their stepparent—and in the beginning consider them "outsiders" who must earn their way in. These relationship differences also impact how the adult views and responds to the child. For example, biological parents may inherently trust their child's explanation for how the milk got spilled while the stepparent wonders if there's more to the story.

There are even more differences when the biological parent has an AS/ASD child.

- If the AS/ASD child has had difficulties with other adult caregivers, the biological parent may fiercely protect the child; the stepparent may feel this is too harsh and controlling. The new parent needs to lean in and learn from the biological parent.
- The biological parent has gained knowledge of AS/ASD through the years; in the beginning, the stepparent is starting at ground zero and, therefore, at a disadvantage to know how to contribute to parenting.
- The biological parent knows what triggers the child and causes dysregulations; the stepparent may view dysregulation as tantrums or as manipulative misbehavior.

- The biological parent budgets for therapy/treatment/resources; the stepparent may not anticipate those types of financial obligations. These therapies and protocols should not be treated as extras like soccer or dance, but needs the child has for growth and further development.
- The biological parent knows where the child started and has watched his/her progress; the stepparent only sees where the child is now and cannot always appreciate their accomplishments.
- In addition, biological siblings are used to the AS/ASD child and accommodating their needs is embraced; stepsiblings are caught off guard and might feel violated by how much life is oriented around the AS/ASD child's needs.

Here are some suggestions to help parents and stepparents bridge these gaps:

Discuss your feelings without placing blame or trying to apply simple solutions (which the AS/ASD parent knows will not work). In the first couple years we suggest the family adapt to the routines already in place for the AS/ASD child; changes can come eventually but should come slowly and only after much discussion between the couple. Stepparents will likely be making many adjustments and sacrifices on behalf of the needs of the AS/ASD child, so biological parents should be compassionate with their frustrations. They should, also, strive to over communicate about family structure to help the stepparent and stepsiblings adapt well.

Date and dine. We also suggest couples make time to date one another, and not allow their couple time to be invaded by problem discussions related to the AS/ASD child or other children. Reserve a business meeting for that! Date nights need to be about strengthening your “usness”, so love and trust foster a safe place to nurture a newly formed family and its complications.

Find some time. Each person in the home needs a hobby. A special needs child takes a lot of energy; you need time alone for self-care so you can have the energy you need to take care of the child. Everyone needs a break! NT siblings, especially, may need an autism-free zone where they can get a break and be the focus of attention from parents. Autism cannot be the only identity of the family, but neither should autism be ignored.

Learn Patience. It will take time to learn about the needs of the child and to merge your family. Find outside support (e.g., a support group or local church ministry) and stay determined in the process.

Learn Organizational Skills. Structure and order are a must for the AS/ASD family. If that is not your forte as a parent, work at it! Taking into consideration a move to a different house in a different school district may be a huge issue for the child on the spectrum, especially if the child has a good IEP team in place and is thriving at their school.

Recognize the importance of spiritual strength. I (Stephanie) don't know where I would be without my faith in God and prayer. Overcoming my “Why did you do this to me, God?” struggle took lots of prayer from myself and others, but now I can see the gift our family has.

Don't neglect the child who is not special needs. Make a strong effort to engage all your children so they don't feel neglected and become resentful of the special needs child. As a

special needs parent, I (Stephanie) was not always successful at this, so I do not say this in judgment.

Find joy in small victories. Not everything is a setback, not everything has to be worked on now. When there is an accomplishment, no matter how small, celebrate it. Joy is contagious. Joy inspires hope.

Work toward “prevention”. Study your child and try to prevent meltdowns instead of always doing meltdown recovery. This does not mean to give in at all costs, but when going to a new environment, for example, anticipate what might trigger the child. What can you do to make him or her successful in the situation and not compromise the whole family night?

Learn to be flexible. Things change; plans change; life happens. You cannot predict every eruption that may happen with a spectrum child so learn to be flexible and adapt.

Finding Reward in the Journey. The average stepfamily journey consists of a few predictable steps: First, a couple falls in love and decides to marry. Second, just as when two rivers merge, the new stepfamily wrestles through several “white water” adjustments as they figure out “how to be family” with one another. And third, the once fractured but now bonded family enjoys smooth rewarding waters brought about by their hard work and determination. In general, a typical stepfamily needs 5-7 years to begin experiencing rewards (some families take longer).

Likewise, AS/ASD stepfamilies will move through similar stages, but given the complexities and various layers of an AS/ASD child the intensity of the rapids can be even greater, and the length of time required to smooth out the white-water torrents may increase. Yet, it can be done. We hope that AS/ASD stepfamilies will be encouraged; finding family harmony is possible, but it will require intentionality and determination.

Autism, when a Parent or Stepparent is on the Spectrum

The above story took into consideration a family blending when a child is on the spectrum, but what about if a stepparent or the child’s biological parent is on the spectrum? JAMA 2019 research that says there’s an 80% heredity factor. It was a 2.1-million-person research done over five countries. That’s substantial research when you have 2.1 million people. Researchers found there’s an 80% hereditary rate for autism, what we used to call high functioning or Asperger’s, without cognitive impairment, which means the likelihood of a parent being on the spectrum is high, but then also you might marry someone on the autism spectrum. Adults who were born before the change in criteria of Autism/Asperger’s in 1994 are often called the “lost generation of autistic adults.” (For more on later in life diagnosis, look up Dr. Stephanie’s article in *Global Journal of Intellectual & Developmental Disabilities*.) There is the possibility that the biological parent or parent the child does not live with in full custody may be on the spectrum. Neurodiverse marriage has its complexities, especially when the diagnosis is not known or is denied, and Christian neurodiverse marriages have many more complexities and possible rigidities with faith and religious beliefs.

Let’s review traits of the autism spectrum that may impact marriage and stepfamily blending. These include cognitive or analytical thinking over emotional and relational thinking, mind blindness, rigidity, black and white thinking, a varying sensory profile, and differences in communication styles. Adults on the spectrum can also dysregulate which may be

internally (shutdown or freeze) or externally (explosive verbally or physically). Neurodiverse marriages have a higher divorce rate than NT to NT marriage, so a remarriage and family blending will be even more complex with the blending of children and all the changes that come with a blending family.

Included now is Ron and Stephanie's discussion from one of their podcasts on this topic.

You can hear the full podcast on the platform, Mental Health News Radio, NeuroDiverse Christian Couples. Below is a transcript of one of their podcasts and is meant to reflect a discussion versus correct writing grammar and formal writing style.

Ron: In our previous segment, we talked a lot about that stepparent. In this case, a new stepfather trying to figure out, "What's the reality for me and my kids?" if he brought children into the new marriage, as it relates to this child in our home, who is on the spectrum. Now, you add to it, "Oh, and my wife's former husband is on the spectrum." You just begin to think about all those little qualities that you mentioned, being a black and white thinker, for example, "No, the schedule does not change. I'm sorry, there can't be any flexibility."

You imagine a stepdad calling the other biological dad going, "Hey, I just ran into something at work and I'm not able to pick up kids at school. Could you go and get them?" "No." The lack of flexibility, the rigidity there that comes out, it's so easy when that happens to assume that is evil intent, if I could put it that way, on the part of the biological parent, like you just are non-cooperative and you don't want to work with us, and to judge it very harshly when it really needs to be seen as part of how that person is wired. That's just not a space they can move into. That flexibility is just not something that they're able to do, or certainly not able to do with ease.

Maybe they could grow into that, but the expectation that you can be reasonable, you just got to reframe it in your mind. Otherwise, I think it would just create a whole lot of frustration and anger coming from the new stepparent. Then it channels into that person's marriage. Let me show you this. Again, just like with the child, it comes back into the couple's relationship. You can see the stepdad getting off that phone call so frustrated, calling his wife, and saying, "He won't pick up the kids." "Well, I know, it's just not something he's able to process right now." "Oh, you're defending him? What's the deal? Why aren't you on my side?"

Very quickly, this becomes not something about the other home, the parent in the other home, but right now it's immediately about you and I and our marriage and our family. If people are not careful, if they're not willing to—You're the one who must flex to understand and work with the limitations of the other individual. If you're not willing to do that, then it's going to ripple conflict into your own relationships and it's going to backfire on you.

Stephanie: In my world, where I work with neurodiverse Christian couples, there was a reason the mom and dad divorced. Neurodiverse marriages are very complex. If the couple was struggling as a married couple to communicate and work as a team; this will not magically improve when they are divorced.

Ron: Yes, there's a backstory.

Stephanie: In many cases, there was undiagnosed autism. Let me do a quick little stand on a platform, and say, this is why clinicians need to understand how to diagnose and identify adult autism. What you think you know about children does not apply when you're working with someone with autism level one in an adult. Masking and camouflaging, this person has learned how to function at work and is probably a CEO and could have a really great job. If you're thinking, "Well, this person is a CEO of a large Fortune 500 company, there is no way possible this person could be on the spectrum," you're already coming from the wrong mind space. You're already in a biased mind space. If you are not trained in how to diagnose someone on the spectrum who is an adult, don't do it. You need to have specialized training.

If someone comes to you and says, "Hey, my spouse or my former spouse or this new stepparent is on the spectrum," you need to do some research and get some training. What does that mean? Traditional therapy does not work. Let me say that again, does not work.

Ron: It does not work. Stephanie, essentially what you're saying is, yes, therapists need to understand that doctors need to, and this new stepfamily member needs to study this and get some understanding. Again, that can feel like, Wait, whoa, all of this seems to be coming back on me. I'm the one having to make accommodations. I'm the one who has to flex in light of the reality. Why don't you take some of the responsibility of making some changes?"

Well, that's part of what we're saying, is there are limits to what that person can—how much they can adapt or change today. It may get there eventually, but for now, embracing that you're the one who is most capable of making some adaptations is probably the better way to go. Would you agree with that?

Stephanie: Absolutely. You have two things that could be happening with that other biological parent. One may be a very strict interpretation, black and white, to that parenting agreement. Five o'clock means five o'clock and not 5:01. That's right. If you come at 5:01, that could cause a meltdown or a situation. If it's every other weekend or this is my Christmas and not your Christmas and I am not changing my Christmas plan, you have a different situation there.

There's not a malintent necessarily not to follow through, but when the day comes, there may not be a follow through.

That's like the other problem. It might be the rigid, "I'm not going to do it. I'm sorry. It's Tuesday. That's your day, figure it out." They could be that rigid. Then there could be the super nice guy who agrees, thinking maybe at that time he could do it, but that day can't change his schedule or it's too overwhelming to change the schedule, and may not pick up the child. Now that's created a problem for the stepparent. We have that whole dynamic. That's a tricky piece sometimes in dealing with that.

Ron: One of the things that I think, Stephanie, somebody who has been married to somebody, maybe you're divorced now, but you understand how they're wired, how they function, or you're the child of or you have a child and you've gotten used to making the accommodations. When new step-people come in, they have to go through this whole grieving process of recognizing what life they thought they were going to lead is not necessarily going to work out the way it was.

I think there's this hard reality of, "You're asking me to live life in fear, in fear of pushing that other person beyond their limits." Living with the fear of getting there at 5:01, there's going to be a meltdown. Nobody wants to live that way. I don't know that it's living with fear. If that's the way you frame it in your mind, then you're going to resent it like crazy. I think you're just going to feel embittered about the whole situation. You're not even sure who you're mad at. You're just mad.

Usually, that ripples out on the people you love. Rather, it's like, "Okay, this is the reality of life. This is what I've got to face. I've got to settle into this so that it doesn't constantly embitter me from the inside."

Stephanie: Right. Because if you're trying to look at the complex picture, there are certainly way more adaptations of this. The most common might be dad was on the spectrum, mom is not. They have a child that was on the spectrum. Now, mom has met someone else who's neurotypical. She had difficulties communicating and working with dad, bio dad, when they were married, when there was motivation from that person to make the marriage work.

Even in a highly motivated situation, that situation still ended up in divorce where communication, black and white thinking, all that, all those things were impacting their marriage and relationship. Sometimes I have to tell the wives, "This person was not easy to deal with when you were in a married situation. Now that you're in separate homes where this person now feels, "Well, this is my home, my domain," you're not going to—"I didn't even like the gluten-free, dairy-free diet when we were doing it together. It's not happening at my house." Guess what? The courts will not make that happen. They may not enforce protocols or diets or supplements.

Or "I don't believe in medication, so I'm not going to give the child medication when they're at my house." There are all these other complicating factors that they didn't agree on in marriage. It's going to be exacerbated. Now, this new stepparent is like, "What gives? Why won't he do it? I'm being asked to do these protocols for our child, for your child, your child, and he isn't even doing the protocols?" You can see that even puts another little wrinkle in there.

Ron: It does. All of those are, again, unfair. Now we have to live in fear of making the other person meltdown or whatever. As long as you're constantly seeing it as, "No, it's got to be fair. They've got to give as much as we have to give," then I think you're just going to keep driving yourself crazy, and everybody around you. It really is this releasing the ability to master this circumstance and make it "fair." That is the best gift you can give to yourself and the people around you.

Stephanie: Let me change the dynamic for the little bit that we have left to talk about. There was a neurodiverse couple and there's a divorce in my clientele. It is likely that if the first husband was the meltdown explosive in a meltdown situation again, the purpose was not domestic violence or to abuse, it was a meltdown but very intense. Just imagine if you've seen a child on the spectrum become dysregulated, what a dysregulation of that magnitude looks like in a grown person in a grown body with grown strength, that might look different.

Maybe there was a divorce, and she met the nicest guy on the planet. Guess what? He too could be on the spectrum, but he's more of the shutdown variety. He's more of the go along to get along, make false agreements, just I'm so happy to be in a marriage, I'll do whatever you say personality. Now, we have this dynamic of the stepparent who is not the biological parent of the autistic child, who may be undiagnosed and in denial of one being on the spectrum.

Talk through it—I just threw that out to you as a case study. Now you have this different system where mom has married someone on the autism spectrum with his own cognitive profile, his own issues, his own rigidities, his own passions, and interests. You would think, well, if this person is on the spectrum, then they will just get this child on the spectrum better. Not necessarily the case.

Stephanie: Just thinking that through, what does that look like?

Ron: First of all, I think, wow, the wife and mom gets a gold medal from me. At the same time, I think she would find herself chasing her tail a lot, because no matter who she's dealing with, her former husband or her current husband, it's like she's not sure that she has. You make a commitment. My current husband makes a commitment. Well, is that just a false agreement? Can I really trust that? In terms of how she deals with her former husband and his rigidity or inability to flex, I'm not sure.

"I guess I know what I have with him, but I can't really rely on him." I can see her feeling lost in all of that and feeling disconnected and unsure. Boy, I sure would want to shore up that couple's marriage. I sure would want to send them to somebody who's a specialist like you so that you can help both of them, educate them on how to work with one another and how to really work towards building trust. Because without that trust, when trust is lacking in a relationship, we know what people do. They tend to either get aggressive and move toward in anger or they tend to withdraw and withhold themselves, self-protect. That doesn't foster a relationship. Think about it, the bigger story going on in the blended family is we're trying to merge. We're trying to integrate ourselves and our lives and our kids and our family and our routines. We're trying to come together, but if we're withdrawing, we're pulling apart. That's working against the bigger picture of the family, not just our marriage, but it's working against the entirety of what it is that we're trying to accomplish.

That's a challenging situation. By the way, one other piece here that we haven't mentioned yet are the neurotypical children who have a stepparent now who perhaps is—

Stephanie: Undiagnosed and in denial of being on the spectrum.

Ron: Not necessarily open towards relationships or warmth. Kids sometimes are pursuing the adults in their world and discovering, "Wow, I can't get anywhere. It must be me." That's what kids do. They tend to move towards shame. "This must be about me. I must be unworthy. I must not be somebody you want to hang around with." They take it on themselves in a negative way.

We would want to guard against that, try to educate the children about what's going on with the new stepparent, and or the step-sibling, and make sure that the neurotypical kids are not blaming themselves for the inability to connect.

Stephanie: That's a very interesting dynamic. Let's say the new stepfather, a common special interest is cars; fixing cars, collecting cars, watching things about cars, cars magazines, cars, cars, cars, and the neurotypical children have zero interest in cars. They maybe want to bond with video games or let's go rock climbing, in those indoor places. The stepparent's like, "You know what, it's cars. You can go to the car shows with me. I'll take you to the car shows. Let's watch car things on TV." Then the neurotypical kids are like, "That's not my interest."

Then the mother can make a mistake of pushing those children towards the husband's interest versus some encouragement that, "If you want to connect to these children, you might have to do some things they like too."

Stephanie: It's one thing for the mom to say, "All right, you're going to play with cars whether you like it or not. We're going to make this happen, so that you have a connection place with my husband." That I would not do at all. It's another thing for her to gently invite, to educate, to sit down and talk with her kids and make sure that they understand that this is about the stepparent, not about them. This is about who he is and how he's wired and designed. It's now you have a choice. You could, from time to time, join him in watching those car shows or something that you vaguely are interested in.

It's an invitation and it's a soft invite, and the child gets to decide whether that's something they want to do from time to time, just as a way of having a connection point. That would be a sacrifice on the child's part. Don't require them, don't demand from them that they do that all the time. The child needs to be free to pursue their own interests and passions and for that to be encouraged.

Stephanie: Sometimes, in undiagnosed adults on the spectrum, clinicians go towards narcissism. If you're not sure what you're dealing with, I always say to the person living it, whether the person is a narcissist or on the spectrum, the way it feels is the same to the wife. The intention motivation is different. The narcissist is there to control, to inflict pain. The person on the spectrum is unintentional and unaware of what's happening.

Yet, if you're living on the other side, one is self-referencing and autism means selfishness, so I'm only aware of myself. Narcissism is about control and controlling you. If you're the person living it, you're in constant negotiation. You can see where this mom is going to be in negotiation, "Okay, if you'll watch a car show with him, I will try to get him to play one of your video games." "Hey, can you do a video game that maybe is car racing?" "Maybe he might be more interested to play that video game with you because it's something."

It put the mom-wife in this situation, especially if there's an ex-spouse that's also on the spectrum. She's a constant negotiator between everybody's needs and the neurotypical and the new step kids. She's constantly in there having to negotiate everyone's. You can imagine that'd be exhausting.

Ron: Yes, exhausting and a burden. Yet, on some level, trying to facilitate some connection would be a helpful thing for her to do. I would want to relieve her of the responsibility or the obligation of making it all work. Orchestrating togetherness between two other people who are not equally motivated towards having a relationship is an exhausting experience. You just can't accomplish that.

Not only is it exhausting, but I would also think it's self-defeating. It's not going to happen. At the end of the day, it's up to the two of them. Now, you can try to do things to educate one or both sides. You can try to create opportunities for them to figure it out. Then, at that point, you got to let it go. You got to pull back a little bit.

Then my question is, who's taking care of mom or wife if she's neurotypical? Who's making sure she's got some connections and some things that are not—I call it, an autism-free space. Sometimes the neurotypical siblings, sometimes the new stepsiblings need an autism-free zone. I'm saying that as positively as I can, even when I talk to nuclear families. For my more neurotypical daughter, she had to have a space where she could be her and things were not running on autism time.

Self-care is so important. If you're caring for an aging parent who has extreme dementia and is unable to care for themselves and is a high-demand person and it's 24-7, nobody can do that forever. Everybody needs a break. You can't blame the aging parent for the condition that they're in. It is what it is. You're trying to love them well as best you know how, and you need a break. Not but, but and.

It's a part of how you care for them well. I think a part of how you care for somebody on the spectrum or your family that's trying to negotiate relationships around that person on the spectrum means you need a break, kids need a break, everybody needs, I love your language, autism-free zone or opportunities for time and space where they don't have to be worried about that or focused just on that. It's a part of self-care that allows you to love those other people well.

Stephanie: Right, to help you love and be when you're in that zone and that is the focus for you know this particular opportunity. Learning to balance both worlds. When you're a stepfamily there's three worlds; there's the stepfamily system, the other system, and my marriage, and now I've got to manage myself. As a mom, I'll speak to, if you don't, you're going to act out yourself. If you are operating out of your reserves and you have just a lot more demands on your life, you're not going to be your best self either.

I hear women tell me, "I've turned into the worst version of myself," and we don't want that either. I'm putting you on the spot here. The complexities of what we've talked about, and we've talked about our own training, and you know what we got in our marriage and family, I feel like sometimes I'm the only one beating this drum. If you agree, do you feel like clinicians, counselors, ministers, coaches, chaplains, pastors, if they're going to work with a neurodiverse couple or neurodiverse step system, do you feel like they should get some additional training or understanding?

If they try to apply traditional approaches and strategies, do you think that would be helpful or can you speak to additional training and specialized areas?

Ron: One of the things we say to our audience all the time, and just last week, I was we were putting on our summit on stepfamily ministry and we were talking to leaders from around the country, and I hammer this home. Stepfamily answers for stepfamily questions.

What we usually do in local churches and premarital counseling and therapy and marriage education courses, parenting courses, what we usually do is first-family answers to stepfamily questions. We inadvertently take what we know, we don't realize it's just about biological family systems, but when a stepfamily asks a question, we apply that first family answer onto a second family circumstance. It doesn't work. Oftentimes it backfires and makes things worse.

I think the exact same thing is true with what we're talking about today. You need to have autism context answers to autism family dynamic questions. It's got to be designed around the specifics of the family, which, by the way, if you're listening and you're just an adult right now, you're just a parent or a step-parent and you're going, "Man, I'm trying to take all of this stuff in, I'm trying to process this and what it means for my life," essentially we're helping you begin to have the autism answers for the questions that your family is experiencing. If you keep trying to apply first-family assumptions about life and relationships and parenting and how children respond and how marriage should go, you're not living that life. You're living in a family with autism. You've got to apply a different set of answers to the questions that you're actually experiencing and living. Otherwise, you'll drive yourself crazy and everybody around you.

Stephanie: So, another little platform soapbox I like to get on, if you disagree with me, you can feel free to disagree with me. Some of my clients would tell me I'm usually the fourth, fifth, sixth counselor that they've had. They've tried intensive weekend getaways that big-name ministries have done. They've told the people, "Hey, we're neurodiverse or one of the people are on the spectrum." They're like, "Well, you'll get the same thing out of the weekend."

There are different expectations. Sometimes the person on the spectrum can't follow all the things that are going on those three-day weekends. If you put a spectrum person in a group of 10, 12 couples for almost 72 hours, that's going to be problematic. If you're applying your intensive weekend or your counseling, again, like you said, a first family approach to a stepfamily approach, if you're applying traditional marriage therapy to a neurodiverse couple, for example, probably in your training with marriage and family, you were probably taught with marriage counseling, "Keep the couple together. Don't do a lot of one-on-one. It's really about the couple and focus on their connection, focus on their intimacy and keep them together."

That is disastrous when you have—if you have a person who is highly stressed, who's going to go into fight or flight over something as simple as you didn't pick up the milk on Saturday, and that could cause an emotional reaction. Can you imagine in a marital situation when the couple is in crisis and they're sitting in your office and the wife starts talking about all the things, what that could do to the person who may have a meltdown.

Ron: Right. That itself then could become, to the other partner, another attachment injury. "See, I can't trust you to even talk about my feelings about what's going on with us. You just

take over the whole situation and go into meltdown. Obviously, what I'm feeling doesn't matter to you." You're right. You've got to have different strategies to. Again, for your audience, we're educating them. Find a counselor, ask good questions on the front end.

Here's a question I coach stepfamilies to ask all the time before finding a therapist. By the way, we have at smartstepfamilies.com, for the first time now, over the last three years, we've started building a list of therapists who have gone through some intensive training that I offer to clinicians. You can get a running start on people that have done their homework.

If you're just calling somebody in your neck of the woods and hoping that they know something about stepfamilies, ask the question, "What would you do differently when working with a blended family than when you're working with a first family?" Same thing with people listening to you. What would you do differently? "Hello, counselor. I'm looking at considering coming to see you. What would you do differently with a atypical person in your—somebody on the spectrum or a marriage that's had somebody or whatever, how would you handle that differently?"

If they say, "Well—" you just say, "Thank you for your time. Have a nice day." If they can spit off two or three things, no matter what they are, it shows you they have spent time thinking about this, doing their homework and it's more likely that's going to be somebody who's going to be able to help you.

Stephanie: We were both recently at a very large counseling event. One of the points that were made was, for a Christian couple, the first place they often go is who?

Ron: Pastor.

Stephanie: People who are not trained or usually had one or two counseling courses maybe, but counseling is not their forte and a step situation and neurodiverse situation are specialized situations. Sometimes there's not training there for just marriage therapy, unless it's your average newlywed struggle, spiritual things where that's where a pastor is equipped. Now these individuals, be it stepfamilies, be it families on the spectrum coming to a minister or pastor, can you talk a little bit to pastors or ministers that we're in a new age now, we're in a different space, and it might be time to update some skills. What would you say to those ministers and pastors listening?

Ron: Oh, sure. The nontraditional family is the new traditional family, and we've all got to update and retool to just keep up with what's going on in the world. A good example is cohabiting couples. I just learned a week ago that the percentage of couples who cohabit before getting married again, so they've been divorced or widowed, the percentage has doubled in the last 20 years, increasingly common in the world today.

Back when I was starting in ministry, if somebody was living together and they came to you for premarital counseling, they didn't tell you, they were ashamed, they were hiding it. Today, it's just sort of expected, doesn't everybody do that? It's like, "Okay, there's a new piece, we've got to retool as we think about sitting down with people and helping them do their life, make decisions about the future, get ready for marriage, whatever the case is."

We all have to do that constantly, and it can be tiring and exhausting. I can't be equipped to work with everybody, with every circumstance in the world, but there are some things I need to be mindful of to some degree and so that's something we should all do.

Stephanie: Even with really great intentions, you could cause harm. If you don't know some of the dynamics of blended families or if you don't know some of the dynamics, especially if you're going to a minister and the minister is really pushing headship, headship, headship, that person's on the spectrum, and, "I've decided that we're spending \$1,000 on my special interest and we're not spending any money on the kids because I've chosen as the head, I would like to spend \$1,000 on my special interest." A minister could really do some harm there.

There are these things you've got to really—just having the basics, even to be humble enough to say, "I don't know. I don't think I'm equipped to help this stepfamily, I really don't know, but I do know the resources where you can." Even if you're not going to be able, like you said, not one minister, not one counselor is meant for a broad general public, there are reasons why there are specialties we can take on board, like I took on board, I don't know stepfamilies.

Ron: We all have limits, but we try to find other people who can fill those gaps. Go to smartstepfamilies.com, and click the link to the clinical and ministry training. You'll find information about both. I do ministry training for leaders and local congregations, but I also do 12-hour, it's two days of training for clinicians who want to understand how to do step-family therapy. It is very focused on the counseling experience, and we do that virtually, so you can be anywhere and be a part of these trainings.

Stephanie: Again, so important. If you're going to work with a specialized family system, you need to know what works and what is harmful because we are image bearers of Christ, and we want to make sure we're being respectful to that family and that system. Also, we've taken an oath to do no harm so we can cause unintentional harm, but we still need to be ready for that. Having the training that you need to work with the family dynamics that you're working with is so important. Thank you so much for doing two segments with me, Ron Deal. Please check out his website and his resources if you are working with blended families. Thank you for joining us today.

In closing this segment, finding a clinician trained both in autism and blended families will be like finding a unicorn. I suggest first focus on understanding autism and getting on the same page about autism. If the couple getting married is neurodiverse, seek a neurodiverse trained coach or therapist. Once you have a foundation of the neurodiversity that is in the family, seek trained help in blending your family. As you have read their two complexities, the blending of families is complex enough, but it increases exponentially if an adult (biological parent or stepparent) is not diagnosed but also is on the autism spectrum.

RRon L. Deal is Founder & President of Smart Stepfamilies™ and Director of FamilyLife Blended® for FamilyLife®. He is a bestselling author, highly sought-after speaker, and therapist specializing in marriage enrichment and blended family education.

We want to include the perspective of a single parent dad who is raising a child on the spectrum to include this single parent perspective. John graciously allowed us to include this blog post.

Challenges, Grief, Hope, Marriage, Special Needs Parenting

On Becoming a Single Parent

Author: John Felagellar

Originally written for Key Ministry, November 2020 (Used with permission)

Last November I had the pleasure of attending the one-man show of a friend who is somewhat of a local celebrity in the Chicago area. The show is quite unique, as it is based on the life of a priest named Father Damien, who was confirmed as a saint by the Catholic Church. Father Damien was the lead missionary to the leper colony in Molokai, Hawaii in the late 1800's. Damien served his community in a variety of ways, helping to build homes and roads, setting up a hospital and organizing medical care, petitioning the religious leaders of his order for more support and resources, and of course, served as the spiritual leader for those stricken with the disease, separated forever from their families and their loved ones. After 15 years working among all of the members of the colony, Damien awoke one morning to soak his feet in some hot water. He discovered that the skin began to peel off, yet he felt no pain. His worst fears now realized, Damien himself had contracted leprosy. In the play, Damien goes to the town center and calls the members of the community together, addressing them, "My children, please come to me. I have always called myself one of you. But now I tell you, I truly am one of you." It was a striking performance, as my friend carried on the rest of the evening with the retelling of a man who loved a group of people that had truly been outcast from society. Father Damien loved them as much as one could, even unto death, and never lost his faith.

One week later, the day after Thanksgiving, I was home doing a variety of minor chores when my wife walked in the house, presumably from running errands. With a half smile on her face, she tapped me twice on the chest and said, "Get your coat, we have to talk in the garage." It was an odd request, one that I met with great trepidation. As we walked out of the house, she mentioned that it was not going to be an easy conversation. The door to the garage was still open, and with no cars parked inside, we sat in two camping chairs that had been set up facing the driveway, reminiscent of how people in my middle-class upbringing hung out in the summer. My wife pulled out an envelope with the name of a law firm at the

top, and proceeded to read me what was, quite seriously, a “Dear John” letter. She began to share the most painful words I have ever heard. It began with generic compliments of me as a wonderful dad, and how we built a great family and she would always love me but...she could no longer love me as my wife. **I sat there listening to the words the words no man ever wants to hear** wash over me, in waves of shock and astonishment. The letter continued to speak about how proud she was of me for the things I was accomplishing, and how God was working in my life—but we were going separate ways and could no longer be married.

She did want us to be co-parents and believed that we could be a model to others in terms of how to handle co-parenting. She finished the letter, handed me the envelope with the letter she had just read. Also enclosed was an official letter from her lawyer, and some brochures with resources for me about how the divorce process would work. She stood up, mentioned that I would need to get a lawyer, possibly take out some new credit cards, and went to grab her purse to leave. I quickly got up from my seat, and hurriedly asked a series of questions, which essentially all amounted to “why?” She just as quickly responded with how it wasn’t one thing, it was a bunch of little things and such. I was in too much of a daze to try and pursue the conversation any further. I watched her walk out of the house through the garage, into her car and drive away. She did not tell me where she was going, and I didn’t even have time to ask about where she, or more importantly, my son would be; he was out with a family friend at the time. I returned into the house, placed my hands on the kitchen counter and tried to catch my breath, all the while my mind racing with thoughts of what to do, what next, who should I call? Somehow, I felt the best move was to physically leave the house, get myself moving and start driving; maybe that would help me to process my next moves and clear my head a little. I had nowhere in particular to go, but I knew I needed to start making phone calls to get opinions and support.

Regardless of whether this might all be a bad dream, or something that might blow over in a few days, I still needed to protect myself. I drove to the nearby parking lot of a big box retail store that was mostly quiet, even though it was still Black Friday. I took my phone out and began to make a mental list of who to contact. The first call was to a lawyer friend, who specialized in special needs families and had been divorced himself. He was supportive but brutally realistic about my situation. He also reminded me of what a quality guy he thought I was and gave me the name of the attorney he used in his own divorce. I followed that up with a call to another special needs dad, who had also been divorced and gone through a very messy separation. He was equally supportive but made it clear how much I had to defend myself and how to best emphasize my rights as a father, especially since our state was strong on fathers’ rights. The next call was the hardest, as I texted a close friend from our old church who knew our family very well and had actually just visited us at home for Thanksgiving. He was stunned, and called me back, thinking I might not be serious. When he realized I wasn’t, I explained what I knew; he agreed to meet me the next day to discuss what had happened and what my next move should be.

That night I slept alone in the house, the first of several nights sleeping alone while my wife and son were presumably at her mother’s house. I wasn’t actually sure, because she never told me. I really couldn’t call what happened *sleep*, as it more resembled crouching in a fetal position; I shifted between mourning for what I had lost and searching my mind for any possible bit of explanation as to why it happened. The next day, I spoke with my friend from

church, then connected with several other folks over the next few days: friends in the counseling world, pastors, ministry leaders, and other special needs parents. None of them could give me an explanation; all of them suggested one theory or another that I essentially couldn't prove. What made those days even more challenging was the fact that my wife would text me with offers to see my son, to have dinner or hang out with him at the mall, where she would meet me for a pick-up and drop-off.

IT WAS IN THOSE MOMENTS, THOSE QUIETER MOMENTS IN BETWEEN THE CALLS AND TEXTS, WAITING FOR MY SON, THAT A STARK REALIZATION CAME OVER ME: WHEN I CONSIDERED ALL OF THE SPECIAL NEEDS DADS I HAD SUPPORTED OVER THE YEARS, ALL OF THE ONES WHO WERE SINGLE, GOING THROUGH OR HAVE BEEN THROUGH DIVORCE, I REALIZED NOW THAT I WAS NOW COUNTED AMONG THEM.

Just as my friend had spoken of Father Damien and his community of lepers in the play just a week before, I had always thought of myself as part of you, but now I was truly "one of you." I was now part of a world I never thought I would be, whether I wanted to be part of or not. Over the next several days, my wife and son returned home. I willingly moved into the guest bedroom, while we began the slow and difficult process of doing life apart, each of us taking responsibility for different days and times with our son. I connected with my friend's lawyer, and we began to develop a legal foundation for my defense and protection in the divorce process. My wife and I continued to meet with our long-time marriage counselor. My wife had actually spoken to this counselor privately before making the decision to go ahead with the divorce. The counselor was still supportive of us working on the marriage if that's what we wanted to do. I certainly did and stated that quite clearly to my wife in our sessions, communicating the love I still had, and how I would do anything to repair and work on the marriage.

My wife, however, was already in a different place, so the negotiation of how and what our divorce would look like was now the focus. I reluctantly agreed. I privately communicated to our counselor that I still held out hope, despite all the odds. The next several months have seen our family become quite different. The large wall calendar where my wife would scribble work nights, doctor appointments and date nights was replaced by a calendar app. Now we both contribute all of those same arrangements, with date nights replaced by lawyer meetings and counseling sessions. We shared the time with our son fairly equally, each of us sharing therapy duties and split time on evenings and weekends, though now neither of us report where or who we'll be with when the other one has our son. I agreed to move into an apartment in March, and so the "single person" rituals of shopping for furniture, packing boxes and cramming them into a storage unit, and securing my buddy and his truck to help me move took up a lot of my spare time. It was truly depressing some days, but very hopeful on others. I enjoyed taking my mind off of the uncomfortable silence that existed in the house then by thinking about what the future holds. In April, amidst the backdrop of COVID and the required quarantines we all experienced, my divorce was finalized with our attorneys and a judge via conference call. I was in incredible pain and expressed as much to friends and family through social media and texts. I even received a text from my friend from the Father Damien play, who let me know he was thinking about me.

While I reflected on how surreal it was to have a 15-year marriage end on a phone call, I also considered how much more difficult this would have been in person, standing in a room

full of people: some I knew and some strangers, but all of them there witnessing the end. I struggled to bring myself back to a place of hope and gratitude and forced myself to remember all of the times I have been led out of dark times by my precious God. **There is one more piece of hope that I hold onto in my darker hours**, and it actually goes back to my friend's Father Damien play. At the end of the play, when after the character has gone through the whole retelling of his life at the leper colony, has now passed away and is metaphorically saying goodbye to this world, he pauses, and turns to a cross hanging above the altar where the show was performed. He raises his hands in prayer before the cross, and slowly and profoundly utters these words: "Whatever I have done, for good, or ill, I am your priest and You are my God. I trust in Your prodigious love." I don't believe it was an accident that I watched that show one week before the events that began to end my marriage unfolded, nor was it an accident that those words were the last I heard that night. They were a truth for Damien, grounded in his faith and love for the God that never abandoned him, even until the very end. I too seek to have that trust, trust in the prodigious love that will carry me through even this passing away.

*Originally written for Key Ministry, November 2020, Reprinted with Permission
Connect with John on his website: www.johnfelageller.com*

Appendix B

Helps and Resources for Parents & Marriages

Autism Spectrum Resources for Marriage & Family, LLC

Dr. Stephanie has put together courses for parents at www.HolmesASR.com.

The following courses will help take your next step in better understanding the Autism Spectrum as a parent or extended family member of someone on the spectrum.

A 22-lesson course for parents who have a child in their elementary school years, *Marriage & Family: Moving Beyond Surviving to Thriving*. This course discusses basics of autism and various protocols and interventions for younger children on the spectrum. Dr. Holmes discusses challenges to marriage and siblings with some practical tips for parents.

A 2-lesson course on a Child's Diagnosis and the Family System.

A 5-lesson course on the specifics of autism in females called AS Female Phenotype.

A 30-lesson course if you have a 10–18-year-old on the spectrum called Spectrum Teens.

A 5-lesson course on the basics of understanding autism, Autism Spectrum: The Basics.

After taking the course, you can reach out to Dr. Stephanie at dr.stephanie@HolmesASR.com for consultation and referrals for putting your new knowledge into action into a next step.



Follow this QR Code to the above Mentioned HolmesASR.com courses!

A workbook for this book to be used in small groups and training is in the works!

Find out more about this free pdf coming soon at: www.christianneurodiversefamilies.com

Our NeuroFam

Are you looking for more support and coaching? You know the basics but are ready to jump into parent coaching or parenting groups.

Meet Coaches and Parents in a NeuroDiverse Family, Jeremy & Charity Rochford.

Team Rochford describes themselves as a mixed Neurotype family, with extensive experience of coaching and mentoring those who need neurodiverse marriage and family help. Jeremy has extensive experience as a speaker and weight loss coach, whilst occasionally generating rip-roaring belly laughs (pun intended) during his stand-up routines. Jeremy and Charity have been together for over 20 years and have created a mutual vibe despite our Neurological differences. When Jeremy was “Neuro-questioning” if he was different, both realized there wasn’t a solid space or family for other families and individuals to belong to on the journey. Then, NeuroFam was born. You can reach out to Team Rochford at <https://www.ourneurofam.com>.

Team Rochford has Group Coaching for Parents at www.christianneurodiversemarriage.com for current groups.

Jeremy and Charity Rochford have been podcast guests on NeuroDiverse Christian Couples, and Jeremy has been a regular member of the special edition podcast, “Just the Guys.”

Check out their video on Dr. Stephanie C. Holmes’ YouTube: It’s Better Than We Ever Imagined!

Walk Right in Ministries

Walk Right In Ministries helps caregivers in special needs families walk abundantly in life, faith and relationships. They offer online counseling for individuals, marriages, and families as well as faith-based caregiver support groups. Their biblical teaching and discipleship training are specifically and uniquely aimed in support of caregivers and provided by therapists and mentors who are themselves experienced caregivers.

They will care for the unique emotional and spiritual needs of your soul. God puts His imprint on every caregiver and family impacted by disability. You are equipped with unique strengths to love and care for your family well. Let them encourage you and help you build strategies that fit YOU — cherishing YOUR family, YOUR circumstances, and YOUR unique temperament design. They want to walk with you in peace, purpose, strong relationships, and resilience — *one step of faith at a time*.

Lisa Jamieson | Co-founder | Caregiver Consultant | Pastoral Counselor | Author-Speaker
Mobile: 612-889-4648 | PO Box 1932, Maple Grove, MN 55311 | www.WalkRightIn.org

Podcasts, Books, and Blogs

Featuring Dr. Stephanie or Rev. Dan Holmes

Dr. Stephanie is an interim host for a secular podcast called Converge Autism Radio sponsored by Springbrook Behavioral Health and can be found at Mental Health News Radio Platform.

Dr. Stephanie and Rev. Dan have their own podcasts where they focus on NeuroDiverse marriage and NeuroDiverse family issues on NeuroDiverse Christian Couples podcast also found at Mental Health News Radio or on the front of their website, www.christianneurodiversemarriage.com.

Follow this QR Code to the Podcast

Dr. Stephanie and Rev. Dan are working on a second book to be released in 2024 on NeuroDiverse Christian Couples! Follow the progress at www.christianneurodiversemarriage.com



Paul Carroll, Autism Dadvocate

Paul Carroll is the founder of Autism Dadvocate. Paul is a believer and in his spare time, hosts amazing guest on Autism Dadvocate and creator of an online dad community at www.AutismDadvocate.org. He is the father of an amazing teen on the spectrum and self-proclaimed, “Dadvocate.”

This episode Dr. Holmes is a guest speaking on marriage and family in a spectrum house: <https://www.autismdadvocate.org/whatdadsautistickidsneedtohearaboutmaritalstrainandhealthydialogue>

John Felageller, Autism Dad and Mentor, Speaker, Joni & Friends IL

John Felageller has spent over 20 years in education, working with children from Infants to Middle School, serving in a variety of roles including Teacher, Mentor Teacher and School Director. John lives in Round Lake, IL and is a single father to his son Christopher (ASD), and is a former Special Education teacher in Chicago, IL. He is a regular contributor to Key Ministry’s Special Needs Family blogs well as other special needs blogs including Hope Anew and The Mighty. John is currently the Relations Manager with Joni & Friends Illinois as well as a special needs father and advocate. I asked John to tell us about his journey and resources.

From John:

In my journey as a special needs father, I have encountered a couple of false assumptions about parenting, and the specific and unique roles that both moms and dads play in raising a child with a disability. It is often expected that the mom is the one who will ultimately be the “manager” of all of that child’s appointments, therapies and specialists. Mom is the one who carries the burden of that child’s quality of life, as a nurturer but also as the one who makes all of the pieces of life fit together. Where is dad? Dad frequently struggles with the diagnosis in his own way, with a very unique kind of grief when it's a male child. Dad mourns the child who will never play competitive sports, graduate from college or start a business. Dad is a fixer, so if he cannot fix his child, he will ultimately throw himself into his work to make enough money so that someone, eventually, will fix it.

This is the narrative I hear so many times, from both moms and dads, people I know personally and stories I hear from around the country. It is not a new dynamic, it is an all too common one, and unfortunately it requires a fundamental shift in the way we see parenting culturally. But on a very personal, individual level, men need to understand who they are in their family, and what their real gifts and responsibilities are in order to thrive. I begin by telling men, regardless of their income or position in life, that they are not their checkbook, that their real value to their family is not based on what they make, but how they show up in their families. Your child is not who you thought they would be...but they are still your child. Connect with them, spend time with them, discover what their interests are. My son will never engage in any formal athletics, but he sure does love watching sports with dad on TV. It also doesn't mean I can't spend time throwing a ball back and forth or shooting hoops with my son, regardless of how bad either of us are at it.

Men are frequently under-resourced and overlooked when it comes to resources in this world, and this is significant since men need to relate to other men to process other dads that can understand their unique ways to process their emotions. Luckily, more of these resources are created all the time, and I encourage dads to seek them out in their own communities or virtually, and where they don't exist, create them! You cannot do this life alone, and even one relationship with another special needs dad that understands can sometimes make all of the difference. I encourage any dad reading this to check out some of the resources I have shared to this work, or to reach out to me with any questions or concerns they may have. Men have a responsibility to their children and marriages, but also to themselves to make sure they are managing their own self-care and emotional state overall.

LinkedIn: John Felageller

Alignable: John Felageller

Special Fathers Network:

www.21stcenturydads.org

www.facebook.com (Dad to Dad-Mentoring fathers of children with special needs)

www.youtube.com (21st century dads)

Connect with John on his
website:www.johnfelageller.com

John has contributed a blog to our site, and been a guest on our podcast August 28, 2023.
<https://www.christianneurodiversemarriage.com/post/challenges-grief-hope-marriage-special-needs-parenting>

Abilities Workshop, Inc.

The Good the Bad and The Godly

If you have a child that has been diagnosed with Autism or another developmental delay, difference or disability, Abilities Workshops are here to help! They are proud to offer a variety of programs and workshops to help you and your family navigate this process. There are series that have been designed for the newly diagnosed family all the way through the families looking for ways to find success as an adult. Jeanetta Bryant, founder of Abilities Workshop, and mother of a daughter on the spectrum, has put together many valuable resources for families. They are a 501(c)(3) Non-Profit. Dr. Holmes had the privilege along with many other professionals to participate in the program, LOVEable, even through the tough stuff. Found at: <https://www.abilitiesworkshop.com/loveable>.

Looking for providers in your area in various specialties? Go to SearchABLE: National Special Needs Resource Database at <https://www.searchablenow.com/>

Abilities Workshop, Inc.

<https://www.abilitiesworkshop.com>

Exceptional Needs Today Magazine

The mission of *Exceptional Needs Today* is to provide support and FREE resources for families, educators, professionals, and self-advocates on a variety of topics of special needs. They work to promote awareness, acceptance, and inclusiveness for ALL people. In fall of 2023, a special edition translated in Spanish will be available for Spanish speakers. Help spread the word! Erica Holmes helped in the translation of this Spanish special edition.

Editor, Amy Tobik

Go to: <https://www.exceptionalneedstoday.com/>

Books

Ron Sandison: Adult on the Autism Spectrum, Professor, Author, Speaker!

Ron Sandison works full time in the mental health field. He is an advisory board member of the Art of Autism and the Els Center of Excellence. Sandison has a Master of Divinity from Oral Roberts University and is the author of *A Parent's Guide to Autism*. He is the founder of Spectrum Inclusion which empowers young people with autism for employment. Sandison speaks at over 70 events a year including 20 plus education conferences. Ron and his wife, Kristen, reside in Rochester Hills, MI, with their daughter, Makayla.

A Parent's Guide to Autism: Practical Advice, Biblical Wisdom is the first Christian book on autism written by an author who has Asperger's Syndrome. It's also the first written by an individual with autism to be published by a national Christian publisher, Charisma House. It is currently available through Barnes & Noble and Amazon.

This guide will help readers have an in-depth understanding of autism, and provide a plan for parents to raise happy, healthy children.

One in every thirty-six children will be diagnosed with autism. More children will be diagnosed with autism than with AIDS, diabetes, and cancer combined. This means every year in America sixty thousand families will receive the diagnosis that their precious son or daughter has an autism spectrum disorder. With diagnosis at such an alarming rate, how can parents be equipped to confidently raise children with autism?

All children can flourish and mature through love.

A Parent's Guide to Autism offers interviews from forty experts, exclusive teaching on bully-proofing children, as well as practical wisdom, biblical knowledge, and life experiences from Ron Sandison. He compassionately shares his own personal struggles with overcoming autism as a minister and professional in the medical field to help parents raise outstanding children.

The book features interviews with more than 40 experts in the autism community and 40 parents of children diagnosed with autism, including:

- Jill Marzo, the mother of Clay Marzo, a professional surfer with Asperger's
- Edie Branning, the mother of Mikey Branning, one of the fastest high school mile runners in the nation
- Dr. Lynn Koegel, founder of Autism Research Center at University of California
- Anthony Ianni, former Michigan State University basketball player and first NCAA Division 1 athlete with autism.
- Kimberley Wineman, the mother of Miss Montana 2012, Alexis Wineman (who is on the spectrum)

sandison456@hotmail.com.

<https://www.spectruminclusion.com>

<https://www.facebook.com/SpectrumRonSandison>

Leisa Williams: Mom, Educator and Author

HOPE WINS, by Leisa Williams.

Leisa was born in 1971 and brought up in Queensland, Australia. She writes from her heart about her life experiences that have come from the school of hard knocks. Her views are tried and tested from many years of working to overcome adversity in her life as well as being founded on her Christian biblical faith, the wise counsel and support from healthcare professionals, and her educational background, which includes a Master of Education degree.

Hope Wins is her first book that links to a devotional series for women called Seeds for Growth.

Hope Wins: Overcoming Feelings of hopelessness in special needs families.

This book is for all those who care a whole awful lot. Perhaps you are battling caregiver fatigue due to additional responsibilities. Leisa offers hope I what others may call a hopeless situation.

Please check out her book and what others are saying about her book, Hope Wins! Leisa has also been a guest on our podcast!

You can find out more at www.leisawilliamsauthor.com

Dancing with Max: A Mother and Son Who Broke Free By Emily Colson

The Amazon description: *The true story of a single mother's love and perseverance, her son's autism diagnosis with its challenges and gifts, and their triumph together over life's toughest obstacles.*

Journey with Emily Colson--daughter of former White House Special Counsel Chuck Colson--as she takes you from her darkest days of pain to her adventure through life. With candor and wit, she shares about her personal battles and heartbreak when, as a suddenly single mother, she discovered that her only child has autism. Emily illuminates the page with vivid imagery--making you laugh, making you cry, and inspiring you to face your own challenges.

This is the story that will inspire you to break free of the barriers that threaten to constrict your life, and Max is the young man who will capture--and even change--your heart. As you learn more about Max and his journey, you'll learn about:

- The incredible power of community
- Facing each day with grace and faith
- Turning your challenges into blessings

In a special prologue and epilogue from Chuck Colson--his most personal writing since *Born Again*--he details how Max's resilient spirit unraveled his thinking and brought out his tender side as a grandfather.

Along the way, you'll discover that Max's disability does not so much define who he is, but reveals who we are. *Dancing with Max* is not a fairy tale with a magical ending. It's a real-

life story of grace, second chances, and fresh starts in spite of life's hardest problems. And Max? Max will make you fall in love with life all over again, leaving you dancing with joy.

I, Stephanie, have had the privilege of leading a workshop with Emily and have read this book. It was important to me to share a single mother's perspective and story as a resource as well.

Appendix C

Connecting Churches and Ministries who want to come along in the journey to serve and minister to families with additional needs!

SOAR

Description From “Doc” about SOAR:

At **SOAR Special Needs** we know that as a parent/caregiver of a child with special needs/disabilities, you want to be **accepted**. To do that, you need to be a part of a **community**. The problem is the lack of resources which makes you feel hopeless and overwhelmed. We believe **you deserve to have resources**. We can relate to the challenges of being a parent/caregiver of an individual with special needs/disabilities which is why we have transformed the lives of over 1000 individuals with special needs/disabilities of all ages, diagnoses, severities, and their families.

Here's how we do it: **1. Join our email list. 2. Sign up for an event. 3. Enjoy your respite!** So, sign up now for our next event. And in the meantime, enjoy our weekly Check-Up with Doc weekly emails. So, you can stop feeling overwhelmed and instead feel embraced!

Here is a little more information for you. SOAR exists to transform the lives of special families and empowers them to SOAR in their local and faith communities. We help answer the three main questions that every family with an individual with a disability has:

1. Will my child ever be able to provide for themselves?
2. Who will take care of my child once I'm gone?
3. Who will take care of me (as a parent/caregiver)?

SOAR helps answer all three of these questions with our current and future programming. Twenty-six percent of the US population are individuals with special needs/disabilities, making them the largest minority group. Therefore, SOAR exists to transform the lives of special families and empowers them to SOAR in their local and faith communities. I would love to share with you some opportunities SOAR provides to help transform your lives.

- **SOAR Summer Camp** - Every summer SOAR Special Needs offers a week-long SOAR Special Needs Summer Day Camp open to all individuals with special needs ages 3 y/o and older. We offer camp in-person from 9 am – 4 pm Monday through Friday. It is a full 40 hours of respite. This is the largest disability day camp in the country! We take all diagnoses and severities, offering a full medical team and behavior team. We focus on one ability, not their disability. Our camps are Vacation Destinations for families with special needs! It can be difficult to take a normal

vacation as a parent of a child with special needs. Our camps are in the greater Kansas City area - take a week's vacation where your child with special needs will have a memorable experience and the best week of their lives. Meanwhile, as parents, you can pour in quality time to your other children who don't get as much 1:1 time with you as you wish. You can do a ton of fun things around Kansas City that you wouldn't normally be able to do. Then in the evening, you can all together as a family have a memorable experience.

- **SOAR Special Needs Facebook page** - keep up to date on our social media - click <https://www.facebook.com/SoarSpecialNeeds>. We also have Twitter, Instagram, Linked-In, and TikTok!
- **SOAR Special Needs Parents Facebook page** - join this page to learn of events, especially for your family, and share items you learn about! Also, this gives you community with other parents who get it! Click <https://www.facebook.com/groups/678942386368059>.
- **SOAR YouTube Page** - Subscribe to our YouTube channel at https://www.youtube.com/channel/UCtxaPe_3w0bSK7VZKthwOag.
- Here is our website link: SOARSpecialNeeds.org. SOAR also offers a lot of local programming in the greater Kansas City area.
- SOAR also hosts one of the nation's largest disability conferences - the Wonderfully Made Disability Conference with tracts for families and for disability ministries/organizations. Our conferences are hosted in Kansas City every October. You can learn more at WonderfullyMadeKC.org.

To learn more check, us out at SOARSpecialNeeds.org or email us at info@SOARSpecialNeeds.org and ask to join our email list.

Are you ready to have your life transformed? Come SOAR with us!

“Doc”

Stephen "Doc" Hunsley, M.D.

SOAR Special Needs Executive Director/Founder

Office: 816-782-SOAR (7627)

Cell: 816-506-1305

SOARSpecialNeeds.org

WonderfullyMadeKC.org

Follow us on: Facebook YouTube

“Doc” also has been a guest on our podcast on July 31, 2023!

Joni & Friends

About Joni & Friends:

Joni & Friends offers multiple support for families. Because at Joni and Friends, we value each person as an image-bearer of God, worthy of dignity and respect! We create a rich, Christ-centered environment at each Family Retreat that is safe and accepting for every member of the family.

People of all abilities need a church where they can fully belong. Our Ministry Mentors will come alongside you and your church to help you identify and remove barriers that impact people with disabilities.

Through training and resources, we can equip you and your church with practical tools for including people of all abilities into the life and ministry of your church, helping people with disabilities find their place in the body of Christ.

“In fact, some parts of the body that seem weakest and least important are actually the most necessary” (I Corinthians 12:22, NLT).

“Joni & Friends offers training for churches to come along families with disabilities and needs”- John Felageller, Joni & Friends, Illinois

Go to <https://joniandfriends.org/>

Look up ministry courses that are right for your church, at the time of this book’s publication the following are courses online offered to churches:

- GlobalAccess Online Conference
- Advocacy 101
- Special Needs Children’s Ministry Certificate Program
- Introductions to Special Needs Children’s Ministry
- Introduction to Special Needs Youth Ministry
- Autism and the Church, an Introduction

Find a family retreat that is right for you at:

<https://joniandfriends.org/family-retreat/>

[John Felageller has been a guest on our podcast as well!](#)

Together We Care (Georgia)

About Together We Care

Together We Care partners with families and people with disabilities to help navigate life’s journey. We assist families in creating, prioritizing, and implementing life plans according to your family’s goals. We also connect you with the resources, volunteers, and organizations that you need to help you facilitate your goals. We utilize our community partnerships, advocacy efforts, and resources to empower you to live the life you desire.

At the time of publication, Together We Care primarily serves GA, but has the heart to spread services throughout the US as the Lord provides and leads!

Jillian Palmiotto is the Founder of the Together Conference and the Founder and Executive Director of Together We Care, a nonprofit organization that focuses on meeting the everyday needs of families impacted by disability as well as equipping organizations for disability inclusion. In 2016, Jillian launched the Together Conference after receiving requests to help other ministry leaders learn the how-tos for developing an inclusive ministry. What began as a small gathering of volunteers, church staff, and pastors has now developed into a nationally known conference. She holds a BA in Early Childhood Education and an MA in Inclusive Education. She is also a licensed minister and served as the disability pastor at Mount Paran Church for seven years.

For more information: jillian.palmiotto@togetherwecarega.org

<https://www.togetherwecarega.org/>

Together We Care Conference

The Together We Care Conference was founded by Jillian Palmiotto in 2016 when she recognized the need for faith communities to have step-by-step plans for creating inclusive special needs and disability ministries. The conference began with a small group of 35 pastors, ministry leaders, and volunteers gathering in a small chapel to learn how they could do a better job of welcoming and including people with disabilities. The Together Conference is unique in that it not only provides the "why" behind needing to include people with disabilities but also provides the "how" to make it happen. It is now recognized as a nationally known conference that is open to all faith communities, private schools, and counseling centers who need help in building inclusive infrastructure into their already existing systems and programs. Join us as we learn how to know better and do better with our disability community.

Find out about the conference at: <https://www.togetherwecarega.org/togetherconference>

Jillian was interviewed on our podcast, <https://www.spreaker.com/user/mhnrnetwork/is-the-body-of-christ-including-all-its->

June 26 of 2023, "Is the Body of Christ Inclusive to All its Members?"

Key Ministries

Key Ministry was founded to help churches welcome families of children with hidden disabilities. Since 2002, we've provided knowledge, innovation, and experience to the worldwide church as it ministers to and with individuals and families of kids with hidden, developmental, and physical disabilities. In addition to being a disability inclusion ministry resource, we find ourselves uniquely called and positioned to serve churches seeking to become more intentional and effective in ministry with children, teens, and adults impacted by mental illness and trauma.

Since 2002, we've provided knowledge, innovation, and experience to the worldwide church as it ministers to and with families of kids with disabilities. While expanding our service to churches, we find ourselves called to a new phase of ministry in which we seek to help families impacted by disability to become connected with local churches where parents and children can worship and grow in faith alongside other Christ-followers.

Our ministry was founded to help churches minister to families of children with hidden disabilities. We find ourselves uniquely called and positioned to serve churches seeking to become more intentional and effective in ministry with children, teens and adults impacted by mental illness, trauma, and developmental disabilities and their families.

The values we strive to reflect in our ministry are ...

Christ-centeredness. We seek to be driven by the mind and spirit of Jesus Christ as revealed through the Word of God and guided by the Holy Spirit.

We champion the local church. Christ established the local church as his representation and reflection in the world. It is through the church that God takes people with different personalities and gifts, unifies them as a single body, and equips them to care for each other and reach the world.

Key Ministry offers training and support for the local church, hosts the Disability and the Church conference yearly, offers support and hope for families with mental health issues or disabilities.

Find out more at: <https://www.keyministry.org/about-key-ministry>

The Church and Autism:

- “Why is church attendance so difficult? Traits associated with autism and common mental health conditions often clash with ‘church culture’ –how we expect people should act when we gather. In addition, there are: Perceptions of how one is being received, Capacity for social interaction
- Self-control critical for church assimilation.”
- Key Ministry can help you welcome and serve and minister to individuals on the autism spectrum better!

-Dr. Stephen Grcevich, MD
President and Founder, Key Ministry

Appendix D

Understanding Autism Spectrum Disorders

Dr. Eric Scalise and Stephanie C. Holmes, MA BCCC

What do music composers Amadeus Mozart and Ludwig Van Beethoven, artists Michelangelo and Vincent Van Gogh, physicists Sir Isaac Newton and Albert Einstein, Renaissance polymath Leonard Da Vinci, President Thomas Jefferson, and Elon Musk have in common? All are known or suspected of fitting somewhere on the autism spectrum. As a “spectrum disorder,” autism represents a wide array of symptoms—from mild to severe—that affect individuals differently. However, a common core of indicators is at play, influencing the neurological development of social skills, empathy, communication, and flexible behavior. This developmental disability crosses every social, racial, ethnic, and socioeconomic group.

Autism is a label feared by parents, a challenge for educators, a subject of movies and books, an often-misunderstood disorder, and is sometimes caught up in a swirl of emotional controversy. So, what drives the need for greater recognition? And has autism reached epidemic proportions? According to research conducted by the Centers for Disease Control (CDC), an estimated one out of thirty-six children have been identified with Autism Spectrum Disorder (ASD), with boys four times more likely to be diagnosed than girls.¹ April 2 of every year is known as World Autism and Awareness Day, and Light it up BLUE is a global initiative that was created to get the message out.

Dr. James Coplan, a neurodevelopment pediatrician from the University of Pennsylvania School of Medicine, maintains that the increase is primarily due to changes in diagnostic criteria. He states that the way current statistics are reviewed is directly related to the number of children who receive services under the heading of ASD. Prior to 1975, there were few, if any, educational rights for “handicapped” children, so no definitive baseline exists. However, Dr. Martha Herbert, a pediatric neurologist at Harvard Research School of Medicine, believes otherwise. Her team examined the rise of rates as a function of the change in diagnostic criteria from the *Diagnostic and Statistical Manual of Mental Disorders-III (DSM-III)* to the *DSM-IV*. Yet, broadening of the criteria still accounts for only 400 percent of the 1200 percent increase from the 1980s, leaving a staggering escalation of 800 percent in the last 25 years not attributable to changes in the diagnostic benchmarks.

Much of the debate centers on incidence versus prevalence rates. Incidence refers to the number of new cases that emerge in the birthrate of a population. Prevalence is the percentage of a population affected by a disease or disorder. To qualify ASD as an epidemic, the incidence based on birthrate must be determined, and this is not known with absolute certainty. Nevertheless, research has clearly shown a significantly higher prevalence of ASD among the present generation, indicating an “explosion” of ASD diagnoses, but not necessarily an epidemic.

Signs and Symptoms

Symptoms of ASD vary from person to person, generally falling into three categories: social impairment, communication difficulties, and repetitive/stereotyped behaviors. [Added in 2015, the *DSM-5* combined these three categories into two. They manifest in a child's early developmental period and impair social, occupational, or other areas of functioning. The *DSM-5* criteria include the following (severity is specified according to the need for support)²:

- Deficits in social communication and social interaction across multiple contexts.
 - In social-emotional reciprocity, ranging from an abnormal social approach to a reduced sharing of interests, emotions, or affect; to the failure to initiate or respond to social interactions.
 - In nonverbal communication, behaviors used for social interaction, ranging from poorly integrated verbal-nonverbal communication; to abnormalities in eye contact and body language; to total lack of facial expressions and nonverbals.
 - In developing, maintaining, and understanding relationships, ranging from difficulties in adjusting behaviors to fit various social contexts; to difficulties in sharing imaginative play or in making friends; to the absence of interests in peers.
- Restricted and repetitive patterns of behavior, interests, or activities.
 - Stereotypical or repetitive motor movements, use of objects or speech (for example, lining up toys, echolalia, or saying idiosyncratic phrases).
 - Insistence on sameness, inflexible adherence to routines or ritualized patterns of verbal/nonverbal behavior (for example, extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greetings, rituals).
 - Highly restricted, fixated interests that are abnormal in focus or intensity.
 - Hyper- or hypo-reactivity to sensory input or an unusual interest in sensory aspects of the environment (for example, apparent indifferences to pain/temperature, adverse responses to specific sounds or textures, excessive smelling/touching of objects, visual fascination with lights or movements).

In the *DSM-IV*, Asperger's Syndrome (named after pediatrician Hans Asperger) was added to the category of Pervasive Development Disorders and referred to as part of the autism spectrum. Since that time, Asperger's has become a common term in the fields of medicine, psychology, and education. A controversial change in the *DSM-5* is the removal of the term Asperger's Syndrome as a distinct syndrome. *The DSM-5* revision team decided the term autism was too broad and hence, was responsible for the increase in autism diagnoses over the past twenty years. The main debate centered on whether "Kanner" or "classical autism" (named after child psychiatrist Leo Kanner) is clinically significant from Asperger's. In the *DSM-IV* and *DSM-IV-TR*, autism included Classic Autism; Asperger's Syndrome; Childhood Disintegrative Disorder; Rhetts's Syndrome; Tourette's Syndrome; and

Pervasive Developmental Disorder, Not Otherwise Specified (PDDNOS); as well as atypical autism.

The Yale School of Medicine analyzed people currently diagnosed with *DSM-IV* criteria and then applied the new *DSM-5* standard on the sample.³ The updated criteria resulted in 75 percent of the sample retaining the diagnosis. The majority of the remaining 25 percent were those previously diagnosed with PDDNOS or Asperger's Syndrome. One major concern for treatment professionals, as well as parents of the diagnosed child, is that those considered to be "higher functioning" may be excluded from the diagnosis and, therefore, much needed services within the educational system.

Dr. Tony Attwood, a world-renowned autism expert, argues that even though the *DSM-5* may exclude Asperger's Syndrome, the *ICD-9/ICD-10* medical classification system used by the World Health Organization retained the terminology and distinction. According to Attwood, those with Asperger's (formerly or sometimes called Aspies) are usually not diagnosed until between the ages of eight and eleven and perhaps even later for girls (ages ten to thirteen). The problem lies with the new *DSM-5* criteria where clinical impairment must be noted before the child turns three. Unfortunately, associated symptoms may not be recognized until the child is school age and struggling with psychosocial skill development among peers. Advocates for Asperger's as a separate disorder must wait to see what the impact will be on future diagnoses, treatment interventions, and resource availability.

Since Asperger's is a relatively recent term, many went through childhood, adolescence, and early adulthood undiagnosed, especially women who blend into mainstream culture better. More adults are being diagnosed in their late twenties and thirties today, usually after a child or close family member is diagnosed. Asperger's also affects marriage because those on the spectrum grapple with reciprocal conversation and difficulty showing empathy and outward expressions of love. It is stated that 80 percent of marriages with an AS/ND partner end in divorce. There is scant information available on counseling NeuroDiverse couples, but traditional marriage counseling tends to be unsuccessful, and non-ASD spouses need to be better educated.

**Asperger's Syndrome is no longer used in the *DSM-5*, and according to the *DSM-5*, those previously diagnosed with Asperger's would now be classified as Autism Level 1.

Etiological Factors

The exact causes of ASD are not fully understood or universally agreed upon. Possible triggers include genetic/chromosomal abnormalities or syndromes (see generational), severe infections that impact the brain (for example, meningitis, encephalitis, celiac disease), metabolic or neurological factors, and exposures to certain toxins or illness during pregnancy (e.g. rubella, some chemicals). Additional considerations include certain prescription drugs taken during pregnancy, such as valproic acid (brand name Depakote, a mood stabilizing drug used to treat epilepsy and migraines), maternal gestational diabetes, bleeding after the first trimester, and premature and/or low birth weight in children. Neuroanatomical studies point to a possible link regarding a combination of brain enlargement in some areas of the brain and reduction in others during prenatal and postnatal development. Other studies are

beginning to explore the potential connection between ASD and certain co-morbid conditions in a person’s peripheral nervous, immune, and gastrointestinal systems.

There are many (added after print—in the medical field, as well as parents) who believe childhood vaccinations especially the MMR (measles-mumps-rubella) vaccine is a primary contributor to ASD. Some point to the age and scheduling of various vaccines given to a child at one time. This particular controversy was based on a 1998 article by British physician Andrew Wakefield. The study was partially retracted in 2004, fully retracted in 2010, and Dr. Wakefield was stripped of his medical license for unethical conduct related in research. Following the initial claims of Dr. Wakefield, several large epidemiological studies were commissioned by the CDC, the American Academy of Pediatrics, the Institute of Medicine, and the US National Academy of Sciences, all of which failed to corroborate the original findings. Nevertheless, some individuals continue to inquire whether or not certain vaccines can “activate” genetic triggers already present, thereby resulting in the development of ASD.

Assessment and Diagnosis

Assessing and diagnosing ASD is complex and time consuming. It can be several years after signs and symptoms first appear before an official diagnosis is given. This tendency may have something to do with the lack of awareness on the part of the parents, understandable caution over misdiagnosing a child’s condition, or concerns regarding a potentially damaging “label.” Screening for ASD is usually comprehensive as there is no single medical test to confirm a diagnosis. Multiple evaluations by healthcare professionals who specialize in developmental disorders are usually necessary (e.g., child psychologists, child psychiatrists, speech pathologists, audiologists, developmental pediatricians, pediatric neurologists, special education teachers). Diagnosis assessments typically include a parental interview; a medical exam, which may incorporate neurological and genetic testing; a hearing test to rule out audiological problems; and a screening for lead poisoning because of its ability to mimic autism-like symptoms. Other evaluative measures may comprise of speech and language assessments, cognitive testing, and adaptive functioning (e.g. the ability to problem solve and demonstrate appropriate social, verbal, and nonverbal skills), and sensory-motor assessment.

Interventions and Treatment Protocols

There are various opinions about “curing” or “reversing symptoms” of ASD. Most researchers understand ASD as a lifelong pervasive development disorder and, therefore, it is not usually discussed in terms of a cure. However, early diagnosis and treatment consistently utilizing a broad range of tailored interventions are believed to be the key. With standard protocols, it is often imperative to have medical supervision (an experienced M.D. or Dr. of Osteopathic Medicine) due to related health risks.

- **Education Services:** By law, schools are not required to provide assistance absent a current (within three years), formal diagnosis. Once a diagnosis is established, a meeting for special services can be scheduled at the child’s school,

which then makes him or her eligible for services under the Individuals with Disabilities Education Act (IDEA). Parents need to brace themselves for what may be a tumultuous journey, especially when the student is on the higher functioning end of the spectrum. Many states have an Autism Society or Autism Advocacy groups who understand state/federal laws regarding special services and can help parents navigate the system.

- An Individualized Educational Plan (IEP) is developed based on test scores, teacher observations, and professional recommendations. Resources available to children can include small group settings to take tests/quizzes, extra time to complete assignments, occupational/speech therapy, social skills training, guidance/counseling for anxiety and transitions and in some cases, one-to-one staff support for children who can do the mainstream work but require behavior assistance. School files typically will not follow into adult life because a diagnostic label for the purpose of educational intervention ends with the twelfth grade. However, the correct diagnosis can make a world of difference in resources and tools for the student from grades K-12.
- Occupational Therapy: Finding an occupational therapist (OT) outside the school setting who understands and works with ASD and Sensory Processing Disorder (SPD) is important. Many children struggle with fine motor skills (e.g. holding a pencil, tying shoes, working a zipper), daily living skills, personal space issues, sensory issues, and self-injury. An OT will evaluate and help determine a tailored plan of action.
- Physical Therapy: ASD children also struggle with gross motor skills (e.g. sitting in a chair, walking gait, skipping, running, standing without falling over). Many students have underdeveloped muscle groups that could be strengthened with physical therapy (PT). Available PT options include dance and movement, gymnastic type skill building, aquatic therapy, Hippotherapy (uses the characteristic movements of a horse to provide sensory-motor input), martial arts, and various types of play therapy. A good PT evaluation can help the parents make choices for their children's muscle tone and muscle group development.
- Social Skills/Social Pragmatics Training: Many children do not grasp social context (e.g. how to read people's body posture or tone, initiate or maintain conversations, initiate play/friendships, or recognize bullying or mean behavior toward them). This is more related to social IQ or etiquette and there are tools parents can incorporate in conjunction with a therapist. Pivotal Response Training for self-management and Developmental, Individual Differences, Relationship-based Approach (DIR, also called "Floor Time") TM are two examples.
- Cognitive-Behavioral Therapy (CBT): ASD is not a mental disease or disorder, yet is often co-morbid with Attention Deficit Disorder, Obsessive Compulsive Disorder, anxiety disorders, hoarding, emotional dysregulation and other behavioral issues. Children will eventually realize they are different from their peers and may need help processing these differences. Individuals often struggle

with anxiety and depression (normal markers may be masked) and the upward trend of ASD teen suicide has become alarming (60 percent contemplate suicide by age 13). Having a competent therapist is a valuable asset to families as they navigate educational milestones and new challenges awaiting each transition.

- **Medical Supervision:** Many in the mainstream medical community believe autism is primarily genetic and structural deficits, thereby emphasizing a combination of behavioral therapies and pharmaceutical treatments. Other professionals, however, strongly believe ASD results from more biological factors (toxins, immune deficiencies, gastrointestinal inflammation). Here, doctors often recommend chelation (removing heavy metals from the body — especially lead, mercury, and arsenic), vitamins and supplements, a gluten/casein-free (GFCF) diet and various options of de-toxing before considering a biomedical treatment.

While ASD remains a complex issue requiring ongoing research, a proactive approach with children and their families is important — letting them know that different does not mean less than or defective. The promise of Jeremiah 29:11 is inclusive for all those with ASD: “For I know the plans I have for you, ‘declares the Lord,’ plans to prosper you and not harm you, plans to give you hope and a future” (NIV).

Authors:

- **Eric Scalise, Ph.D.**, is the former vice president of the American Association of Christian Counselors. He is a Licensed Professional Counselor, a Licensed Marriage and Family Therapist, the former Department Chair for the Counseling Program at Regent University in Virginia Beach, Virginia. He has more than thirty-two years of clinical and professional experience in the mental health field. Eric is an author, a national and international conference speaker, and frequently consults with organizations, clinicians, ministry leaders, and churches on a variety of issues.
- **Stephanie C. Holmes, Ed.D., MA** is a Certified Autism Specialist, a Credentialed Christian Counselor with the Georgia Board of Examiners for Christian Counselors and Therapists, a Board Certified Christian Counselor with the International Board of Christian Counselors and was formerly a Licensed Professional Counselor in North Carolina. When Stephanie’s oldest daughter was diagnosed with Asperger’s Syndrome, she changed her focus to the world of educational plans and understanding how to help special needs’ students in the classroom and their families. Her current coaching and counseling ministry focuses on NeuroDiverse Christian Couples.

END NOTES:

1. Centers for Disease Control Prevention. Retrieved from cdc.gov/ncbddd/autism/data.html.
2. American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Washington, DC: American Psychiatric Publishing, p. 50-59.
3. McPartland, C.; Reichow, B. & Volkmar F.R. (2012) Sensitivity and Specificity of Proposed DSM-5 Diagnostic Criteria for Autism Spectrum Disorder. *Journal of American Academy of Child and Adolescent Psychiatry*, 51, 368-383.

Reprinted from *Christian Counseling Today* Vol. 20, No. 2, Childhood Development Disorders. With permission from the American Association of Christian Counselors.

Adolescence and Autism Spectrum: Counseling Teens on the Autism Spectrum

Dr. Stephanie C. Holmes

Article Originally Published for Members of the AACC, Republished with Permission of the AACC

Adolescence is a time of physical changes, educational transitions, social group dynamic changes, and hormonal and emotional regulation issues. How do these changes affect an adolescent with Asperger's Syndrome/Autism Spectrum Disorder (AS/ASD)? These life cycle changes and transitions cause additional challenges and stressors to persons on the autism spectrum. According to the latest National Health Statistic Reports in 2015, there is indication that 1 in 45 students have been diagnosed on the autism spectrum and rates are increasing. The reasons for this increase remain largely unknown. This 2% may not seem statistically significant, but if you consider that the National Center for Education Statistics estimated 50.4 million students in the public school system enrolled for the 2016-2017 school year, this indicates the likelihood of 1,008,000 students who are diagnosed on the autism spectrum in the public school system alone (Zablotsky et al., 2015).

Therefore, the need for mental health practitioners to not only understand AS/ASD has risen, but so has the need for understanding that most techniques taught in mental health degree programs makes an assumption that the person in the counseling room has a neuro-typically (NT) developing brain. The AS/ASD brain is wired quite differently which is crucial to understanding what techniques may be more effective with the AS/ASD person.

The basic criteria for Autism Spectrum Disorder 299.00 (F84.0) in the current Diagnostic Statistical Manual (DSM-5, 2013) include:

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history.
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (p. 50).

These criteria illustrate some issues that will make reciprocal peer relationships difficult.

One of the first issues to address with a spectrum teen, or a family of a spectrum teen, is explaining what AS/ASD is and is not. Depending on when the diagnosis occurred, the teen may have been labeled as Asperger's Syndrome (note: they usually prefer you use that terminology) or ASD level 1. The therapist needs to assess what the spectrum individual, and the family understands and believes about the autism spectrum. One of the first barriers is the lack of understanding of AS/ASD, and the first part of therapy may need to include psychoeducation. Many falsely believe AS/ASD is a mental illness and therefore there is a cure/treatment. A second part of the education process is understanding the neuroscience behind AS/ASD because brain wiring affects any co-morbid mental health issues.

Neurobiology of AS/ASD

In the AACC DVD Neurobiology course, Sibcy (2016) explains that the middle prefrontal cortex has nine major functions: body regulation, attuned communication, emotional balance, response flexibility, insight, empathy (theory of mind and mindsight), fear modulation, accessing intuition, and morality. Sibcy (2016) further explains that the role of interpersonal experience affects the wiring of the brain wherein highly stressful environments “set the autonomic nervous system on high alert making a person sympathetically dominant.” All of these brain regions are affected by the brain wiring in the AS/ASD person. Because an AS/ASD person has issues with these brain functions and they experience challenges in interpersonal issues, they tend to have higher rate of stressful interpersonal relationships. As the brain continues to develop in adolescence interpersonal experiences can further affect how the brain is wiring and storing social interactions or thoughts about self and abilities in social interactions.

AS/ASD Brain Wiring

Rubin (Murphy, 2011) in an interview explains AS/ASD wiring:

As autism is a neurological disorder that makes it difficult for a child to predict the actions of other people, their ability to cope with social expectations in less predictable environments, make transitions, and use others a source of emotional support is often compromised. Thus, many children with autism are coping with a heightened degree of stress.

Rubin spoke locally in Atlanta at the 2013 Monarch Annual Inclusion Conference through Emory Autism Center. Rubin (2013) said that AS/ASD persons process social stimuli (face, tone, speech sounds) in regions of the brain typically reserved for processing non-biological images and sounds. This makes it difficult for the AS/ASD person to predict actions of others and why they are accused often of over-reacting to various stimuli and situations. For example, the NT child knows instinctively that the teacher’s or parents’ voice is the stimuli to attend to when instruction is given. The AS/ASD brain often does not see the human voice as any more important than any other sensory stimuli present.

Parents and teachers may think the child heard the instruction and is being willfully disobedient or stubborn, but the person may not have registered or processed the information as relevant, and therefore, did not attune or encode the information (Rubin, 2013.) Rubin (2016) stated that attachment is the fuel for brain development and some children are genetically advantaged for this development but for those who attach to objects and people as equals, they do not get the same enjoyment from social interactions. What is actually different or wired differently in the AS/ASD brain?

Based on the brain imaging available in 2006, Wallis (2006) noted:

- Frontal Lobes: greatly enlarged, excessive white matter, puzzling signs of inflammation
- Corpus Callosum: information does not flow freely between the hemispheres
- Amygdala (Limbic System): 15-20% larger, misperceives what is an actual threat

- Hippocampus: 10-15% larger storing factual information but does not store and file other data systemically/ ASD person constantly trying to retrieve from short term memory
- More local communication centers and not long distance or global brain communication
- ASD brain has more white matter than other brains and less gray matter

As brain imaging has improved researchers such as Buxbaum and Hof (2013) add:

- AS/ASD have 5-10% more total brain volume (TBV)
- White matter develops slower and there is an overgrowth of gray matter in adolescence*
- Hippocampus has difficulty with integration of information associated with memory
- Decrease amounts of gray matter in the brainstem contributes to issues with sensory modulation input * (According to Wassink et al. (2007) the overgrowth of gray matter in adolescence contributes to abnormalities in serotonin transports).
- (Emerging but unpublished research indicates that dosing and medications work differently and require lower dosing for AS/ASD are implicated with further research needed)

Why is brain anatomy and its affects important to counseling/therapy? Herbert (2005) stated,

Autism is caused by hard-wired changes in early brain development that are largely due to abnormal genetics. The impact of genetics may be considerably modified by epigenetics. Since autism is a static encephalopathy with a fixed, genetically programmed core neurobiological, or brain abnormality, treatment can lead to better adaptation, but autism is inherently incurable (pp.357-358).

This psychoeducation helps set the tone for treatment goals to adapt, cope, and to become aware of emotional regulation issues for both the parent and adolescent. This education helps prevent emotional dis-regulation issues usually called meltdowns. Meltdowns are different than willful disobedience or “temper tantrums”. In therapy, the adolescent will learn techniques to identify and label emotions, understand the impact of his or her emotions and needs on others, communicate needs, and then regulate mood which do not come naturally due to lack of theory of mind.

Adolescence ASD and Mental Health Issues:

Special Interests

One of the criteria of AS/ASD is a specific or restrictive special interest. These special interests are like ions; they can be positively or negatively charged. The special/restrictive interest need not be odd or out of the ordinary. It is the intensity and how the person responds when interrupted from that interest that becomes an issue (Holmes, 2016). Discussing the special interest is a way into the inner world of the AS/ASD client, according to Attwood (Holmes, 2016). Attwood states if a special interest is given proper boundaries and understanding, a special interest may be crafted or developed into a career, as in the case of Dr. Temple Grandin (Holmes, 2016). Attwood said special interests cross a line clinically when there are refusal behaviors to stop the activity or it has become irresistible or compulsive. Some special interests may become harmful or some may contribute to issues of identity confusion. Attwood stated:

Many times AS/ASD persons may be experiencing being bullied or feel powerless socially which can lead to the desire to have power. This can lead to fascination with guns and weaponry feeding the idea that violence is the solution to the problem (Holmes, 2016, p. 37).

As previously stated, if an AS/ASD is being bullied by someone of the same sex they can develop interest in the opposite gender and believe that becoming the opposite gender will solve their social issues. Effects of bullying left untreated can lead to an interest in power/retribution or gender confusion and other mental health concerns. In the same 2016 interview, Attwood said if an AS/ASD youth is struggling with depression or dark moods this could lead to a special interest in drugs, alcohol, self-harm, or junk food as a method of emotional regulation. In recent news, we heard the term “Asperger’s” used with the shooters Adam Lanza (Sandy Hook) and James Holmes (Colorado theater). Attwood stated that Lanza and Holmes are not the norm for AS/ASD adolescents, but it brings up the subject of assessing the impact of being socially isolated and the impact of violent games and movies in persons who lack theory of mind and mindsight. It is not the games or movies that are a problem, according to Attwood, it is the thought that these things will make them more powerful accompanied with the absence of theory of mind that create the potential clinical concern (Holmes, 2016).

A possible secondary diagnosis based on gender identity issues due to restrictive issues gender on can create a special interest of the opposite sex. The current American client may accept this as natural or genetic. A much more descriptive article on this subject matter is on the AACC blog, but in an interview with Attwood he stated:

When someone on the spectrum comes to believe something is truth, it becomes truth to them, much like in history when it was adamantly believed there was a geo-centric (earth) model of the universe. Even when evidence is brought forth the fact that the universe is heliocentric (sun), it was met with opposition, despite the new scientific facts. Simply arguing with facts will bring fierce opposition—even rebuke (Holmes, May 2016, p. 36).

When a person on the spectrum locks their mind into a belief system, it becomes a perception of truth wherein arguing tends to fortify their position. Dr. Attwood discussed that the neural pathways of AS/ASD persons can become entrenched passionately in the area of gender identification. Most persons on the autism spectrum are bullied by those of their same

sex and find it easier to engage socially with the opposite sex. Therefore, they can come to believe that life would be better if they were the opposite gender. Gender identity needs to be handled with care and compassion. Dr. Attwood categorizes those *he feels* are genuinely dealing with transgender issues as those who since childhood felt they were the opposite gender. However, for those with AS/ASD some of the ideas behind the gender confusion are the belief that becoming the opposite gender will make their social issues disappear or contribute to happiness.

Dr. Attwood said not to confront the gender issue head on but to do what he calls the “Psychological Archeology” as to how they came to this belief. Help them discover their sense of self and their attitudes about themselves, and how they formed the gender identity based on social interactions and feedback received about self from the peer group. “Aspies tend to base sense of self criticism by peers and their feelings of inferiority because they feel different,” according to Attwood (Holmes, May 2016, p. 37).

In adolescence, the desire to be accepted is strong and because of sensory issues and not feeling attracted to the opposite sex at the same time as their peers, (as they are usually 3-5 years behind emotionally/maturity) they may come to believe or be told by peers they are asexual, bisexual or transgender. This is why it is so important that AS/ASD persons be told about their AS/ASD so that the differences are more correctly attributed to their brain wiring and not their sexuality or gender.

Dr. Attwood explained that spectrum teens have a fractured sense of self and the thought that something is making them unable to be accepted by their peers attracts them to a group known for inclusivity (such as LGBTQA?) which may fuel their gender or sexuality confusion. The thoughts about being different, combined with a need of acceptance may be a powerful catalyst to pursue gender change. Attwood offers hope that most special interest has a 3-5 year phase and argues that making any permanent anatomical changes during this phase is not beneficial. Dr. Attwood counsels, “By waiting until a child is older to tell those about their diagnosis can denote something shameful about it when in fact they need to learn to embrace the AS/ASD as part of who they are to better understand these differences” (Holmes, May 2016, p. 38).

Depression Attacks/Suicidal Ideation

Fitzgerald (2007), Storch et al. (2013), Carter (2009), Nauert (2016), Wolke and Copeland (2013), and other research as well as interviews with Attwood (Holmes 2014 & 2016) indicate that bullies have often targeted teens with AS/ASD. Being bullied has severe psychological impact (Wolke & Copeland, 2013).

Attwood often states that autism is not a sickness in which one suffers with or suffers from, it is how that person is treated by others that often causes the suffering (Holmes, 2016). With the differences in brain anatomy and how thoughts become entrenched, how does bullying or being isolated affect those with AS/ASD?

Brain research indicates that spectrum teens have enlarged amygdalae. The amygdala is the part of the limbic system that activates fight/flight/freeze. Their brains also show different wiring in the prefrontal cortex, which is the part responsible for making decisions

and understanding long-term consequences of behaviors. Dr. Attwood gave an analogy of a gazelle grazing on a savannah and hearing a twig snap. The gazelle does not reason various scenarios for the sound. The sound activates survival mode in the gazelle that a predator is close and it runs from the perceived danger. Remember, Sibcy (2016) said the brain encodes emotionally charged experiences and “highly stressful situations set the autonomic nervous system on high alert making the person more sympathetically dominant.” Social situations, sensory issues, negative interactions, transitions, compliance interactions can all be encoded as stressful to the spectrum brain. If we take into account the enlarged amygdala that may overreact to *perceived* danger/threat, the absence of a peer repair system, positive self-image, and a pre-frontal cortex that is not giving advice about possible consequences of behaviors of the current flood of emotions, the teen may have a depression attack, according to Attwood (Holmes, 2014).

Most clinicians recognize suicidal warning signs and behaviors of those who may be at risk for suicidal ideation. But if you have an AS/ASD teen who already has a blunted affect, who’s routines and grades have not changed, who have not given away a prized possession (special interests) or even thought through a suicide plan, it becomes difficult to analyze when an AS/ASD teen is at risk for suicide (Holmes, 2104). Attwood explains,

The spectrum teen could wake up in the morning and be fine, and seem normal to parents, then something happens at school to trigger anxiety or negative thoughts and they go into a reaction/survival mode. With a warning system of the brain at hyper-alert and with a prefrontal cortex responding that for example, running out of the building into the street in front of a car is not a good idea, the spectrum teen could inadvertently kill himself because of something that happened in the moment. I call these depression attacks, which are quite like the suddenness of panic attacks but based on depressed mood, or feelings that come on quickly and intensely (Holmes, 2014, p. 22).

Talking often with AS/ASD persons about their processing and feelings and asking about these thoughts are necessary to help discuss the long term/permanent consequences of self-harm or suicide can help process the issue in a logical way. Mindfulness and emotional regulation techniques are also helpful. AS/ASD persons lacking theory of mind and having alexithymia may not be aware in time and space as to what they are feeling, much less how that impacts those around him or her.

Techniques on mindfulness, relaxation, coping, and even some DBT can help. educate the teen of how thoughts fuel emotions. CBT techniques such as thought stopping and replacing, building self-talk scripts to replace those negative thoughts can help as well. Chalfant (2011) offers more detailed guidelines for working with anxiety and autism. One of the most important therapeutic tools, according to Attwood, is a friend. Teens want to belong and feel accepted. Help the teen find an outlet perhaps based on a special interest (chess club, animals, Latin club, etc.) or a way to volunteer to build the sense of social group and belonging (Holmes, 2014).

Baker & McMahon’s (2014) neuroscience research and practice illustrate that a strength based therapeutic approach and creating structured opportunities to achieve and build positive self-image and relationships can provide some neuro-relational repair in a disconnected brain.

Ledgin (2002) adds helping the teen find a role model suspected of AS/ASD perhaps even in a shared special interest can help build positive self-esteem and embracement of the AS/ASD. Ledgin's (2002) short list of persons suspected to have AS/ASD traits include but are not limited to: Thomas Jefferson, Emily Dickinson, Marie Currie, Charles Darwin, Mozart, Albert Einstein, Orson Welles, Bela Bartok, and Gregor Mendel.

Eating Disorders

Kalyva (2008), Allely (2013), Arnold (2016), DuDova et al. (2015) as well many other researchers in the field of AS/ASD, point to a link between AS/ASD and what appears to be anorexia nervosa. Kalyva (2008) reports that AS girls tend to be underweight and have different eating attitudes compared to peers. The behaviors and ideas about food intake or exercise may fit the criteria for anorexia, furthermore clinicians may believe it is treatment resistant anorexia, but Attwood (Holmes, 2015) said it could be a food or exercise special interest and should not be treated the same way clinically. Attwood explains that in effort to fit in a spectrum female may think, "If only I was thinner, I would fit in better" or may have entrenched thoughts about certain foods or exercises that have become entrenched as truth. Dr. Attwood said, "Usual treatment for anorexia is group therapy or a group home or family sessions, but this will not work with an a spectrum female and it would be easy to assume the anorexia is treatment resistant" (Holmes, 2015).

The reason group and family sessions does not work is because the motivation of the eating issue is different for the AS girl. "Psychological Archeology" and CBT individual therapy focuses on discovering the thoughts of self and food and find out if the food issues are even sensory related is the better approach. Jennifer O-Toole (2014) a woman on the spectrum stated at an Atlanta Autism conference, "If you are a therapist and your female client is underweight, has experienced food issues, has had issues with relationships such as domestic violence, struggles with depression and anxiety, and seems socially naïve, you want to consider she has Asperger's Syndrome and may not be diagnosed."

Conclusion

Since 1994 when Asperger's was introduced as a diagnosis to 2013 when the term was removed from American diagnostics, the term has changed from Asperger's/HFA (high functioning autism) to Autism Spectrum Disorder. What remains constant is the rate of diagnosis on the spectrum continues to rise. The children diagnosed in the 1990s-2000s are now adolescents and young adults struggling with the challenges of AS/ASD in a NT social world. Many received a later diagnosis, and some as adults have not yet received the diagnosis but with the mental health challenges that can accompany AS/ASD (usually due to how NTs have treated them) and their navigation of socially engaged world, the need to understand and provide appropriate, compassionate, and adequate mental health counseling has risen as well.

References

- APA (2013). *Diagnostic and statistical manual of mental disorder, 5th ed.* Washington, DC: APA Publishing.
- Arnold, C. (2016). The invisible link between autism and anorexia. *Spectrum*. Retrieved from <https://spectrumnews.org/features/deep-dive/the-invisible-link-between-autism-and-anorexia/>
- Baker, P. and White-McMahon (2014). *The hopeful brain: Neurorelational repair for disconnected children and youth.* USA: Lulu Publishing Services.
- Buxbaum, J. and Hof, P. (2012). *The neuroscience of Autism Spectrum Disorders.* UK: Academic Press.
- Carter, S. (2009). Bullying of students with Asperger's Syndrome. *Issues in Comprehensive Pediatric Nursing* 32, 145-154.
- Chalfant, A. (2011). *Managing anxiety in people with autism: A treatment guide for parents, teachers, and mental health professionals.* USA: Woodbine House.
- Dudova, I., Kucourkova, J., and Koutek, J. (2015). Early on-set anorexia nervosa in girls with Asperger's Syndrome. *Journal of Neuropsychiatric Disease and Treatment* 11, 1639-1643.
- Fitzgerald, M. (2007). Suicide and Asperger's Syndrome: An editorial. *Crisis* 28(1) 1-3.
- Herbert, M. (2005). Autism: A brain disorder or a disorder that affects the brain? *Clinical Neuropsychiatry* 2 (6), 354-379.
- Holmes, S. (2013, November 25). American Association of Christian Counselors blog. *Are special needs' kids targeted for bullying?* Retrieved from <http://www.aacc.net/2013/11/25/are-special-needs-kids-targeted-for-bullying/>
- Holmes, S. (Nov.-Dec. 2014). Spectrum Teens. *Autism/Asperger's Digest.* Arlington TX: Future Horizons Press.
- Holmes, S. (2015, December 5). American Association of Christian Counselors blog. *Complex special interests with AS/ASD part 2: When a special interest becomes a clinical issue.* Retrieved from <http://www.aacc.net/2015/09/01/complex-special-interests-with-asasd-part-2-when-a-special-interest-becomes-a-clinical-issue/>
- Holmes, S. (February-April 2016). Special Interests: Like an ion they can be positively or negatively charges. An interview with Dr. Tony Attwood. *Autism/Asperger's Digest.* Arlington, TX: Future Horizons Press.
- Kalyva, E. (2008). Comparison of eating attitudes between adolescent girls with and without Asperger's Syndrome: Daughters' and mothers' reports. *Journal of Autism Developmental Disorders* 39, 480-486.
- Ledgin, N. (2002). *Asperger's and self-esteem: Insight through famous role models.* Arlington, TX: Future Horizons Press.
- Murphy, C. (January 2011). An Interview with Emily Rubin. *ASHA Leader* 16. Retrieved from <http://leader.pubs.asha.org/article.aspx?articleid=2278962>
- National Health Statistics Reports (2015, November 13). Estimated prevalence of autism and other development disabilities following questionnaire changes in the 2014 national health interview survey. Retrieved from

<https://www.autismspeaks.org/science/science-news/new-government-survey-pegs-autism-prevalence-1-45>

- Nauert, R. (2012). Special needs don't depress kids: Being bullied or left out does. *PsychCentral*. Retrieved from: <http://psychcentral.com/news/2012/04/30/special-needs-dont-depress-kids-%E2%80%93-being-bullied-or-left-out-does/38021.html>
- O-Toole, J. (2014). Future Horizons Conference. Atlanta, GA
- Rubin, E. (2013 July 26). Differentiating instruction based upon the unique neuroscience of ASD (elementary ages). Monarch Annual Inclusion Conference. Atlanta, GA.
- Rubin, E. (2016 February 19). Emily Rubin of Marcus Autism Center speaks. Retrieved from <https://www.youtube.com/watch?v=ihZ2ydYrF-g>
- Sibcy, G. (Presenter). (2016). NEUR 103: Applications: Practice Models and Neurobiology. *Neurobiology 2.0* [DVD]. American Association of Christian Counselors.
- Storch, E., S., Sulkowski, M., Nadeau, J., Lewin, A., Arnold, E., Mutch, P., Jones, A., and Tanya, K. (2013). The phenomenology and clinical correlates of suicidal thoughts and behaviors in youth with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 43(10), 2450-2459.
- Wallis, C. (2006 May 15). New insights into the hidden world of autism. *Time Magazine* 167 (20).
- Wassink, T., Hazlett, H., Arndt., Schellenberg, G., Dawson, G., and Piven, J. (June 2007). Cerebral cortical gray matter overgrowth and functional variation of the serotonin transporter gene in autism. *Arch Gen Psychiatry* 64 (6), 709-717.
- Zablotsky, B., Black, L., Maenner, M., Schieve, L., & Blumberg, S. (November 2015). Estimated prevalence of autism and other developmental disabilities following questionnaire change in the 2014 national health interview survey. *National Health Statistics Report*, 87, 1-10. Retrieved from: <http://www.cdc.gov/nchs/data/nhsr/nhsr087.pdf>

Spectrum Teens: The Issues They Face

An interview with Dr. Tony Attwood by Stephanie C. Holmes, Ed.D., Certified Autism Specialist

Previously Printed in *Autism Digest*, Used with Permission

**At the time of this interview Aspie was still a term of endearment*

Adolescence is a challenging time whether or not you have autism spectrum disorder/Asperger's, but spectrum teens certainly have a few more challenges to face during this already tumultuous stage of life. Currently the rate of ASD diagnosis is 4:1 boy to girls. Girls tend to be misdiagnosed or missed altogether because their brain wiring helps them be less conspicuous. However, being less conspicuous in their symptoms does not mean that they struggle less in the adolescent years.

My first question to Dr. Attwood was: What transition points for spectrum teens tend to be the most problematic to them? His answer, pointed and humorous, began with, "First of all, we must remember that those with Asperger's (ASD) do not have an illness or disease from which they suffer. There are not stomachaches or headaches or physical symptoms as such to cause suffering. Those with Asperger's (SD) suffer most because of peer groups around them. Neurotypical teenagers are toxic creatures. Teenagers are toxic to mental health. The suffering endured is not because of Asperger's. It is because of the attitude and degradation of others in the peer group."

Dr. Attwood and I discussed the already changing nature of the academic environment that happens in middle and high school, compared to that of elementary and primary school. These factors add to the stressors of all adolescents but are compounded in the spectrum teen who do not handle change well. In addition to the environment changing to pre-pubescent teenagers, the nature and level of schoolwork is changing. Academic expectations are increased, and more independent work is expected with more complex and abstract concepts to grapple with in middle school. The classwork and homework is expected to be more self-directed and a lecture-only teaching style is not best approach for the mostly visual learning style of the spectrum teen.

To add to this, most teachers begin to assign team or group work and projects, which can set the spectrum teen up for stress, anxiety, and teasing as they work alongside neurotypical teenagers. Another significant change is from the one-teacher classroom in elementary school to a seven-period day with different teachers, different teacher personalities and expectations, and more organizational skills required in changing classrooms through the day.

I asked Dr. Attwood to list what he considered to be the highest stressors spectrum teens face outside of changing classwork expectations. His first response was, "An Aspie losing a close friend is a catastrophic event. It is like being in the middle of a tumultuous ocean without a life raft any longer. The friend was the life raft." He added, "A good friend for an Aspie is better than Prozac or any other psychotropic drug. A good friend can change things dramatically for the Aspie. So, the loss of a close friend is one of the worst things that can happen to an Aspie teenager."

The stressors that Dr. Attwood said puts spectrum teens at higher concern for clinical levels of depression and anxiety include, but are not limited to, rejection from peers, humiliation, or bullying and teasing. Dr. Attwood explains that NT teens who get occasional teasing or rejection from other peer cliques have a social group that helps repair the damage from the cruel words or rejection. If Sally the NT teen is picked on by a group of girls for what she wore or how she did her hair, she has a peer group that comes alongside her and says, “Oh Sally, that’s not true. They were just being mean.” Or the friends come around her to support her and reaffirm her worth to their group. Spectrum teens tend to be alone and do not have a group to “offer emotional repair.”

“What happens then,” explains Dr. Attwood, “is without repair the Aspie teen tends to *believe* what was said and internalize those thoughts. Cruel words are seeds that bear fruit, and they are powerful and wounding. The Aspie believes the bully.”

In a conference held in Atlanta, Georgia, in October 2012, Dr. Attwood listed the common causes for clinical levels of depression in AS Teens. He said the first factor is being alone or alienated, which can set the spectrum teen up for being bullied, teased and ridiculed. But another major aspect is trying to act “NT.” Dr. Attwood explained, “Most Aspie teens realize they are different. They tend to study their NT peers as if they are studying a play with actors. They try to emulate their NT peers to the best of their ability, and this is emotionally and mentally exhausting.” They figure out that the “real me” is different and must not be “good enough,” so I need to act or be someone else so that I can “earn” friends. This feeling of being watched and acting can also lead to clinical levels of chronic anxiety where the spectrum teen feels powerless, inferior, and puts constant pressure on themselves to fit in with their peers.

What troubled me most as a mother of a spectrum teen, was when Dr. Attwood stated at the Atlanta conference that one in three spectrum teens have clinical levels of depression and are at risk of “depression attacks” that can come on suddenly and seemingly without warning to NT parents, just as an anxiety attack. I began to take this seriously and research the effects of this clinical depression and found many studies stating suicidal ideation is on the rise among Spectrum Teens. Dr. Attwood illustrated what could be the perfect storm to trigger a depression attack in the spectrum teen. First, we are trying to get spectrum teens to be educated in an environment with teenagers, and that alone is already toxic to overall mental health. Spectrum teens have empathetic attunement, which is an extraordinary “sixth-sense ability” to read negativity in an environment. They may not be able to read faces and pick up on social cues, but they sense when there is danger or negative emotions around them. If the teen is also feeling isolated or being bullied, therein lies the opportunity for a depression attack to be triggered.

Brain research shows that spectrum teens have an enlarged amygdala. The amygdala is part of the limbic/emotional system and is part of the fight/flight/freeze reaction system. Their brains also have different wiring in the pre-frontal cortex, which is responsible for understanding actions and long-term consequences and in planning behaviors. Dr. Attwood gave the analogy of a gazelle or other grazing animal on the savannah. If the animal hears a twig snap or senses a predator, the gazelle does not reason out what the options could be as to why it heard the sound. The gazelle goes into survival mode and reacts; it runs from

perceived danger. The spectrum teen brain has some similar features to this animalistic instinct of survival.

If we take into account an enlarged amygdala—which may overreact to perceived danger or threat—no repair system to help the teen figure out better options, and a pre-frontal cortex that may not be giving messages about permanent consequences to current feelings, the spectrum teen could have a depression attack. Clinicians are trained to recognize warning signs and behaviors of those who may be at risk for suicidal ideation and suicidal tendencies. When you have a spectrum teen who already may have blunted affect, whose routine or grades have not changed, who has not given away prized possessions or thought through a suicide plan in advance, it makes it more difficult to analyze when a spectrum teen is at risk for a depression attack.

Dr. Attwood said, “The Aspie teen could wake up in the morning and be fine and seem normal to the parents. Then something happens at school at the beginning of the day that triggers anxiety or negative thoughts and they go into reaction mode. Without a pre-frontal cortex responding that running out of the building into the street in front of the bus could result in a permanent consequence, and the warning system of the brain at hyper-alert, the spectrum teen could be at higher risk to harm themselves or inadvertently kill themselves because of something that happened in that moment.”

Spectrum teens are also at risk for anorexia and gender identity confusion as a result of bullying by same-gender peers, and drug and alcohol consumption in order to self-medicate from feelings of isolation.

(See more about gender identity and spectrum teens on our blog at www.christianneurodiversemarriage.com. There is an additional interview there on this topic).

I asked Dr. Attwood what he saw as solutions or resources to help spectrum teens during this tumultuous time of adolescence. His first suggestion was that spectrum teens have a therapist who is trained in cognitive-behavioral therapy with an understanding of ASD. Even though autism/Asperger’s Syndrome is not a disorder that causes depression or anxiety, the treatment by others and the feeling that they are different certainly puts them at a higher risk. Having a trusted person to talk to can be helpful. He said the best medicine and help for spectrum teens is a supportive peer group.

Dr. Attwood travels internationally quite extensively and in his travels he said flight attendants wear pins representing the flag of the language they speak so that international passengers have someone who can interpret and can communicate with those who speak a different language. He feels what would be excellent for teens on the spectrum is for school systems to identify safe peers who are able to understand and “speak” the spectrum language. These safe peers could be taught how to help teens on the autism spectrum navigate the social waters of school life and be a haven to kids and teens who might have struggles with social issues during the day.

“Just like these flight attendants wear the pin representing the flag of the language they speak, these safe peers could wear a jigsaw puzzle pin indicating to those on the spectrum that they are safe to communicate with and could be helpful to them.” These safe peers could be a buffer between the spectrum teen and bullies. They could also help the neurodivergent teen determine the character of predators and help navigate in dangerous social situations.

Best of all, they could help with “repair” work if the spectrum teen has a negative social encounter at school.

It would be amazing and helpful if our school systems would do more to educate students not just “not to bully,” but how to reach out to those who are most susceptible to it, how to be a help to them. A popular myth is that “Aspies prefer to be alone.” This is not truth. Spectrum teens tend to seclude themselves when they are rejected and isolated from the peer group. Creating their own world, obsessions with gaming or reading, is oftentimes an escape or coping skill to feeling alone, and they resign themselves to being alone. They don’t choose to be alone.

Dr. Attwood said in a situation where a student is being bullied or teased and it is agonizing to go to school, “Homeschooling them can save lives.” As parents and educators, be vigilant of that student that “doesn’t quite fit in.” Get to them individually and get to know their strengths and what they have to offer to their community. Help them find a way to find a niche at school through clubs or activities. Having a therapist to work with as a preventative measure is never a bad idea, and helping to create positive peer relationships can help them tremendously.

The Growing Concern of Suicide and Asperger's/Autism

Stephanie C. Holmes, Ed.D., BCCC, Certified Autism Specialist

Previously Published in *Confessions of a Christian Counselor* and the AACC blog, Used with Permission

How many suicides are enough to warrant concern that there is a problem in this country with our suicide rate?

Just one. One should be enough to make us pause and wonder why someone would feel that suicide was the best solution to his/her situation. There are 30,000 deaths every year in this country due to suicide.

Every seventeen minutes a suicide is completed and every forty-two seconds someone is attempting suicide. Studies show 80 to 90 percent of those who commit suicide had a mental health issue. The rates of suicide are rising among teens with high functioning autism (formerly called Asperger's/Aspies). There is not a study to provide empirical numbers, but those working with AS teens are suggesting that 50 percent of spectrum teens have contemplated or attempted suicide and spectrum teens are at a 40 to 50 percent higher risk of completing suicide than their neurotypical (NT) counterparts.

Consider these two scenarios:

Zach (not his real name), age eighteen, is an honor student about to be inducted into a national honor society. Lately, his family feels he has been turning some poor choices around and for once he is really talking about college and pursuing a choice career. There have been no changes in his friend circles, no talk of depression in the past three to four months. Things seem to be looking up! The future is bright. The family couldn't be prouder of his high school and fencing achievements.

Susie (not her real name) is a thirteen-year-old eighth grader. She makes all A's, and everyone around her tells her of her beauty and intelligence. She has a few good friends and is one of the teacher's favorites. There have been some middle school girl drama and some ups and downs in friendships. Recently, a mean girl targeted her to exclude her from a group going on a school trip that she had highly anticipated since sixth grade. Her family is concerned about the exclusion/ bullying and asked her how she was processing all of this. She gave all the right answers, her grades never dropped, and her routine did not change.

Which student would you be more concerned about contemplating or completing suicide? We are taught that the common markers are the onset of depression, talking about death or wishing they had never been born, giving away treasured items, talks of actual plans, acute anxiety, or changes in friends or routines. What if the parents of each were concerned and went to mental health providers but were turned away? What if these students came to you as a counselor or minister? Do they present suicide risk?

The answer to the question as to which one was at higher risk is—both! Both students were diagnosed with Asperger's (when the term was used). "Susie" attempted and daydreamed about suicide but did not complete the action. Zach, unfortunately, successfully took his life.

What makes a spectrum teen at higher risk? The number one reason is social isolation and/or rejection, which lowers an already low self-esteem. What adds to this feeling of

rejection is that many times spectrum teens do have decent friendships and get invited to parties in elementary school, then there is sudden shift in middle school.

Middle school is the time the teen notices he is “different.” Other students seem to notice it too. Those who had been friends in elementary school suddenly distanced themselves. This is confusing for the spectrum teen. “Why were we friends in fifth grade but not sixth grade? What did I do? How can I make them like me again?”

A blog called “Your Little Professor” said: “In the teenage world where everyone feels insecure, teens that appear different are voted off the island. Spectrum teens often have mannerisms deemed odd by other teens. One teen talks in a loud unmodulated voice, avoids eye contact, interrupts others, violates the physical space of others, and constantly steers the topic of conversation to his or her favorite odd topic.”

Sometimes these teens appear aloof, cold, and selfish or like they “want to be loners.” Adolescence is a time when student are seeking identity and peer approval. What is one to do when all attempts to make friends results in being shunned or bullied?

What else is changing in middle school? Schoolwork is getting harder. The “hand holding” and encouragement many received in elementary school is no longer the case in middle school. School expectations are different. Students are expected to do public presentations and worse for spectrum kids and teens, group projects. When teachers allow the students to pick their own groups, guess who is often left out and then has to reluctantly form what gets referred to as the “loser group” with the others that were also not included.

We have all heard of “anxiety attacks” but Dr. Tony Attwood said spectrum teens are prone to “depression attacks.” A spectrum teen can wake up fine in the morning exhibiting no signs of anxiety or depression and have a trigger at school, such as being bullied, getting a low grade on an assignment, getting a feeling that a teacher does not like them, breaking up with a friend, and suddenly be under what he calls a “depression attack.”

The depression comes on intensely and, paired with a pre-frontal cortex that does not always see permanent consequences of actions, is not getting a “do not do it” message from the executive part of their brain. They see suicide as an immediate response to end sudden, intense pain, and thoughts of it being something that cannot be undone is not usually part of their pre-frontal cortex thinking process.

Attwood adds that inherent to the condition is the tendency to catastrophize. Because of this tendency, there are challenges to regulate their emotions. Add to that the fact that the amygdala of a spectrum teen tends to be 10-15 percent larger than in Neurotypicals, which can inflate the “danger alerts” in the fight/flight/freeze system. What would have been a one on the scale for an NT individual could easily have registered as a 10 to the person on the spectrum.

The overactive amygdala sends signals that start the heart racing, adrenaline production, stomach churning, and as Attwood said, “It is like the Aspie is the last to know about his or her heightened emotions. He appears to be just as surprised as the observer when emotions have escalated.” He added that in addition to an enlarged amygdala there is less white fiber between the amygdala and frontal lobe. The frontal lobes are not getting the signals that the system is under duress and there is little interaction from the executive function, which in NTs would be saying, “Calm down, hitting them will get you in trouble. Breaking that is not a good idea.”

Spectrum teens have made an art form of “making a mountain out of a molehill” to many people, but what we need to understand is that what may be a molehill to one IS a mountain to the spectrum teen. I agree with Dr. Attwood that cognitive-behavioral therapy is crucial for spectrum teens to get often. We should not wait until we think the teen has exhibited something to “need” therapy.

A good therapist who understands the autism spectrum and issues of adolescence can help the teen explore various issues before it is a major problem. Attwood said that spectrum teens should be getting regular “mental health checkups” to help navigate the tumultuous times of adolescence as preventive measures to help with “depression attacks” and learn positive self-talk and recognize catastrophizing before they take a permanent action for a temporary problem.

I urge therapists and ministers to take time to understand Autism Level 1 (previously Asperger’s). It appears to be becoming a matter of life and death in this population of teens.

Supporting Families with child on the Autism Spectrum: How Can You Help?

Stephanie C. Holmes, Ed.D., BCCC, Certified Autism Specialist
Previously Printed in *Confessions of a Christian Counselor*

As I was driving my oldest daughter to high school recently, I briefly reflected on those tumultuous years of elementary school. I was a prisoner to my cell phone, looking every five minutes to see if the school would be calling me to come pick up my daughter—*again!* Those were tough years. I thought back to the day of her first expulsion from kindergarten and the sinking feeling that this behavior I was seeing could be “that thing” I learned about in graduate school—Asperger’s Syndrome.

Even though I held a graduate degree in counseling and an undergraduate degree in psychology, knowledge of the symptoms of a disorder does nothing to help you live with a lifelong developmental disorder in your child. The thought was terrifying to me. The school system referred me to the TEACCH Autism Program, a program available to parents in North Carolina. TEACCH was instrumental in diagnosing not only my oldest daughter with Asperger’s and mild OCD, but, later, my youngest daughter with PDDNOS and mild ADHD.

TEACCH was a wealth of information to me when I was overwhelmed and trying to educate myself on what to do to help my children. One of the biggest things TEACCH did was give me permission to reach out for support. I’m an independent soul who tries to conquer the world on my own and asking for help is not in my repertoire of tools for coping.

I was told to call the North Carolina Autism Society (every state has one) for support and help in advocating for my daughter’s Individualized Education Plan (IEP) in the school system. *Why do I need help?* I thought. *I can do that on my own. I am an educated person.* I soon learned that nothing could be further from the truth.

Connect Families with Support and Resources

In working with special needs children and their families, one of the greatest things you can do is give special needs families permission to seek support, then connect them with appropriate resources. Individual or family counseling alone will not be enough. Every state and community needs an organization like TEACCH. As a Christian counselor or caregiver, I encourage you to take time to get to know what is available in your area. If there aren’t many resources, support groups, and educational classes for parents, consider partnering with other clinicians to make these available. Pray about how God would use you to raise awareness and provide support to families in your community with a special needs child.

Reaching out for help is one of the best decisions I ever made. I realized quickly that the school system took advantage of my lack of knowledge of the laws concerning disabilities in school and simply wanted to label my daughter as a “conduct disorder” child and toss her in a BED/BEH (behavior focused classroom) room. I was in over my head. I called the NC Autism Society, became a member, and sought out help and support. I have no idea why I was embarrassed to admit I needed help with a disorder I knew nothing about, but I was.

An advocate came with me to a crucial IEP meeting, and as she spoke, quoted laws and mandates, and advocated for my child, I was so glad she was on my side! I was impressed. She fought to keep my child out of the secluded behavior-focused classroom and fought for us to get a shadow/aid for my daughter. Not only that, the advocate also did a demonstration in my daughter's class to help the students better understand my daughter's autism and her sensory needs. This normalized some things for her classmates and helped them understand what was going on when they saw her act out, throw a fit, or have a public meltdown.

The children who saw that demonstration never bullied my child again and seemed to give her grace when teachers and other adults could not. NC Autism Society helped me, supported me, and inspired me to advocate and speak up for other children. They helped empower me to do for others what they did for me.

As a counselor, I encourage you to tell your special needs' families to reach out, because getting adequate support is crucial to the health of the entire family. Visit Autism Speaks for a directory of available resources in your state.

Encourage Screening and Early Diagnosis

Many times, parents notice autistic-type behaviors but say, "We just don't want to label her," or, "We think he'll grow out of it," or, "We don't want her to feel different from the other kids." However, if a child is acting out at school or not excelling, the school system is already giving him a label of either "conduct issue" or "lazy."

Why not get the appropriate evaluation and get the *right* label? The child in question already knows she is different, so why not celebrate that difference and get the proper label so that the child can get the help they need at school, as well as other treatments and therapies? These may include occupational therapy, speech therapy, physical therapy, specialized diets, chelation, hippotherapy, vitamins and supplements, and more. I admit it can all be overwhelming, but early intervention and finding the right protocol for a child will be a worthwhile investment.

Unfortunately, the school system is not always a child's advocate, so parents must step up to the plate. Often, classes are overcrowded, and teachers are overworked. However, there are programs in place to help special needs' children ... but parents must take the initiative to seek them out. With the help of advocates and support, my husband and I fought for what our daughter needed. Today, she is very successful in a mainstream class gifted program at our local public school.

Life in the Trenches

From our own experience as well as working with other families, I have three main pieces of advice:

- Encourage families to reach out for help and connect them with appropriate resources and support groups in the local community.

- Encourage screening and early diagnosis whenever Autism Spectrum Disorder is suspected, in order to gain access to needed treatments and therapy.
- Help parents advocate for their child in school and capitalize on their strengths, wherever they are on the spectrum.

The journey is not easy, by any means. That's why no family should do it alone. My daughter went from an autism-secluded classroom to a mainstream class with a shadow/aid, to a behavior-focused class, to home school, to a two-teacher team in mainstream, to a regular mainstream class.

There have been many struggles and trials along the way, but when I look at where she is now, I am eternally grateful for the people God placed in our life to educate us about autism, connect us with resources, and help us advocate for our daughter. Will you be that for someone else?

Autism Awareness: Should I Tell My Child *He/She Is* on the Spectrum?

Stephanie C. Holmes, Ed.D., BCCC

Certified Autism Specialist

Previously Printed in *Confessions of a Christian Counselor*

One in thirty-six. That's the newly released estimate of school-aged children who are on the autism Spectrum. One of the questions I'm most often asked is, "Should I tell my child that they are different from other children? Should I tell them about their diagnosis?" Many parents fear labeling their child and the stigma associated with diagnostic labels. Although I understand these fears, we live in a world of labels, and I explain to parents, "Your child is different and because of that people around him or her are going to label them. I would prefer they get the correct label."

What If My Child Is Labeled?

Often, children on the spectrum who are not diagnosed or not labeled will be victim to misinterpretations of their behaviors and mannerisms by the adults in charge. It is a fact of life that a child who has learning challenges or who is on the spectrum will not receive the help that can be provided through a 504 plan or Individualized Education Plan (IEP) without the proper diagnostic label.

One educational website shares: "Only certain classifications of disability are eligible for an IEP, and students who do not meet those classifications but still require some assistance to be able to participate fully in school would be candidates for a 504 plan." Disabilities or challenges that meet the requirements for service are specifically outlined. The school system is not required to give services based on a parent's hunch or because a child is failing school or has various behaviors of concern. In order for the school to put a plan in place, the label or diagnosis is required.

What If My Child Is Treated Differently?

Understandably, many parents share, "I don't want my child to feel that he or she is different. I don't want them to be treated differently." I can tell you that your child will eventually figure out that they are different, that they are "differently abled." My concern is when a child on the spectrum is in a school setting and is not diagnosed, teachers form other labels like, "disruptive," "defiant," "lazy," "difficult," "selfish," "rude," or, "does not belong in this classroom."

That is why I say I prefer that children to get the proper label. Eventually, the child will figure out that they are different. I like to take a proactive approach with my children and let them know that they are different, and different does not mean bad or less than. Different can be good.

Our Family's Story

When I told my daughter she had Asperger's Syndrome, she was in the fourth grade. I wanted her to know that *autism* was only one label or word that describes her behavior. These are the labels I described to my daughter. I said, "Sydney, I want to explain to you why you have been having such a hard time at school and making friends, but before I do I want to tell you some very important things about yourself."

"First of all, you are a child of God. You are made in His image and here are some things the Bible says about that. It means you are:

- loved (John 3:16).
- chosen (1 Thessalonians 1:4).
- a new creation (2 Corinthians 6:13).
- blessed (Galatians 3:9).
- victorious (Revelation 12:11).
- an heir in Christ (John 17:11).
- fearfully and Wonderfully Made (Psalm 139:14).
- forgiven (Ephesians 1:7).

I took the time to read these verses to her and speak them over her. I further explained:

"You are not only a child of God, but you are my child and I love you unconditionally. There is nothing you can do that will make me not love you. I will defend you and protect you at school and anywhere because you are forever my child.

"You are gifted and talented in music and art. You have a loving heart for animals.

"You may not know how to tell people that you love them, but I know that in your heart, you love people and you try to help people in your way.

"You are a wonderful reader. You are gifted in math and science. You are so many wonderful things. These things are who you are.

But you know how you have had struggles at school, how you keep getting in trouble, and you have trouble making friends? That is because you have something called *autism*. Autism makes it difficult for your brain to understand some things, and it is why you get frustrated sometimes and things bother you so easily. That is autism.

"I will never allow you to use autism as an excuse to fail. I will never allow you to use autism as an excuse for bad behavior. I will also remind you that you have Asperger's, but you get to decide if Asperger's has you. Asperger's is a condition you have.

"It does not have to define who you are, because you are so many other wonderful things. Asperger's causes some things to be hard, but it has some

gifts, too, like your memory for details, your ability to solve math, and your wonderful vocabulary.”

How Sydney Responded

“What did your daughter do about her diagnosis?” some people ask. “How did she take it?” These thoughts have been reinforced for the past five years. Let me share the essay Sydney just wrote for her ninth-grade composition. Her prompt was, “Write about a core belief that you hold dearly and be willing to share with the class.” Below is that 500-word essay.

“People all over the world face challenges, struggles, and difficulties. The question is: Will they let that obstacle define them, or will they rise to overcome what was thought to be impossible? Many believe actions are set in stone, and it is not possible to overcome. There are few who do not. I believe that no matter who you are or what you have done, anyone can overcome an obstacle. No matter how hard, how difficult, or how impossible it seems, anyone can overcome an obstacle.

“There was this girl I used to know, who was very close to me. She had trouble in school, with friends, and nearly every aspect of her social life. This is because she has Asperger’s Syndrome, also known as very high-functioning autism. When she was first diagnosed, the diagnosis was believed to be more prevalent in boys. Few teachers and few administrators knew how to help this girl succeed in school. The special education room was not a proper fit, but she found it difficult to be in the mainstream classroom. When she was confused or having an emotional meltdown, the teachers misinterpreted this behavior as disrespectful or disobedient behavior.

“In reality, she was communicating she needed help or further clarification of the instructions. Unfortunately, the girl was suspended for over fifty days of school and expelled from five schools by her third-grade year. Many people, including people her parents thought to be supportive family friends, gave up on her. They thought she would never overcome her problems or her struggles. They thought she was confined to a path [that] would lead to Juvenile Detention.

“This same girl who struggled so much in elementary school became an honor roll student throughout middle school. She is commonly referred to [now] as a “goody two-shoes.”

“In case you have not put the pieces together, that girl was me. How is this possible? Well, I refused to allow others to define me by my behavior and my diagnosis. I was determined to prove to the teachers and the adults around me that their beliefs about me were wrong. I overcame my problems. My faith helped me overcome one struggle at a time. I decided that my diagnosis was

not an excuse to fail. I will have to deal with more in my life than my fellow peers, but I refuse to let my problems limit who I can become.

“I hope that when my family has finalized adoption that I can help the children who come into our home to believe in themselves. Children in the foster care system have had many struggles and have had many people give up on them. I believe that my story can inspire them to believe that their past does not define who they can become. Nothing is impossible when you set your mind to achieve what you believe.”

(You can hear Sydney read this herself at YouTube: Dr. Stephanie C. Holmes: Overcoming a Label)

Do not be afraid of labels. Diagnostic labels can help you help your child get the services they need. Remind them of who they are and as Christians their identity is in Christ, not in a label but autism is part of who they are neurologically, and this is nothing to be ashamed of.

Has Your ASD/SPD Client or Child Turned into the “Grinch”?

Stephanie C. Holmes, Ed.D., BCCC, Certified Autism Specialist

Used with Permission and Previously Published in *Autism/Asperger's Digest* and AACC Blogsite

We have all heard the expression “the sights and sounds of Christmas.” When I think of the Christmas season, I think about love, laughter, hugs, family gatherings, buying gifts, decorating, food, Christmas lights, and all the sights and sounds and aromas of Christmas.

Don't get me wrong, of course, Christmas is about the birth of our Savior, and He is the “Reason for the Season,” but there are many components to the Christmas season that are very, very sensory-related. This can be problematic for your client or your child who is on the autism spectrum or has been diagnosed with sensory processing disorder (SPD).

Sensory Aversive or Sensory Seeking?

Sensory issues are complex, and this simple definition does not do the issue justice, but sensory stimuli enter through our five senses, and, for those who have sensory processing issues, their brains do not process the information the same way the neurotypical brain does. I call this the problem of “too.” Sensory issues are real to ASD/SPD persons—they are not just making it up to be difficult.

As my daughter would commonly say, that is “too loud,” or “too bright,” or “too scratchy,” or “too spicy,” or “too” something. Sensory issues have two broad categories with many subcategories, but a person diagnosed with a sensory issue can be sensory aversive or sensory seeking. The aversive person is the person that will tend to use the word “too.” That new sweater grandma gave me is “too itchy” or “too lacy” or “too red,” or that new hair bow hurts my head, or that food is “too spicy.”

As a parent, until I understood the complexities of sensory issues I thought, *Man she complains about everything! She has to be one of the most ungrateful children on the planet.* There is a sensory seeking side, as well. The sensory seeker loves to feel things, touch it all, see the bright lights and is enticed by sensory overload, but this overload then is followed by hyperactivity or a sensory crash. So, one child who is aversive may hate going to see the Christmas lights, talking to Santa, or being in a mall with throngs of people, while the sensory seeking child gets completely energized and hyperactive in the same situation.

It's All About the Brain

Two of the brain-based issues at work here are the corpus callosum and the amygdala. In the ASD brain, the amygdala is 15 to 20 percent larger than average. In simple terms, this part of the brain sizes up what is a threat and is involved in “fight or flight.” Part of the issue with sensory integration is that the amygdala sizes up many sensory things as a threat, which

causes the person to go into fight or flight. To the average onlooker, the person appears to be having a tantrum or at best is a “fussy child.”

The corpus callosum is smaller in the ASD brain. A 2006 *TIME* magazine article reports, “The ASD corpus callosum works more like an improv jam session, instead of a beautiful orchestra.” So, sensations are not always accurately communicated across the brain hemispheres. One of the best ways to help ASD/SPD clients is by teaching them to regulate sensory issues. When a child with sensory issues is over-stimulated, there will be meltdowns, crankiness, irritability, anxiety, or ADHD-type behaviors. This time of year can really seem to turn your ASD/SPD client, or child, into the Grinch!

Easy Preventative Measures

I like to encourage people to be preventative and creative. First, assess what things tend to trigger the child. Work with the family to help them take some of the following actions. If the lights are too bright at the Christmas light show, the parents can let their child take some shades. If the sounds are an issue, parents can take some earmuffs and a device that plays music the child likes. Parents can talk to relatives ahead of time about gifts for the child to avoid embarrassing moments. Parents can explain the sensory issues and give some appropriate gift ideas. It is also important to practice with the child what is the appropriate thing to say or do if offered a food or gift they do not like.

If hugs are an issue and the parents know that Aunt Helen loves those hugs and kisses, talk with the child about what they might feel is an OK greeting—one hug, an air hug, a hand shake, etc. Encourage the parents to explain to the touchy-feely aunt that this is the way she can express a greeting and that squeeze hugs or a dozen kisses are going to cause an issue.

One of the best resources for an ASD/SPD child is a great Occupational Therapist (OT). OTs are experts in helping you assess the exact sensory issues and how to better regulate them. Sensory issues and how to manage them can be a huge key to the child’s success.

If you are looking for further educational resources, take a look at the free video at aspergerexperts2.com, which was created by two young men with Asperger’s. From their own experience, they explain the number one thing we can do to help those on the spectrum. Hint? Help them regulate those sensory issues! After Christmas, we head into New Year’s Parties and then Valentines. There is always a sensory overload holiday right around every corner, but as a Christian counselor, you can make a difference.

Noah's Voice Non-speaking Man Advocates for Big Changes

Dr. Stephanie Holmes interviews the Seback Family

Reprinted with permission from *Autism Parent Magazine*, This article was featured in Issue 88 – Knowledge is Power

I met the Seback family two years ago when Noah was first learning how to use the letter board to communicate. Watching Noah now share his thoughts and opinions and advocating is inspirational. In my office, I interviewed Noah while his mother, as his communication partner, held the letter board and wrote down the letters Noah was spelling out. His movements are not always precise because he struggles with motor planning deficits; thus he requires some motor coaching and has not yet progressed to independent typing. Noah is passionate about advocacy for inclusion and equal communication rights for nonverbal persons on the spectrum.

Today, Noah and his parents want to share the disappointments, frustrations, challenges, and triumphs he has experienced through his educational history and as he inspires other families to seek out communication techniques (such as pointing to spell on a letter board) to help connect nonverbal-speaking persons through communication to the greater community.

An exclusive interview with Noah Seback and his parents, David and Nadine

Stephanie: When did you first suspect Noah was possibly on the autism spectrum?

Nadine: His development was typical, meeting developmental milestones up until about 13 months of age. We were new parents, and we didn't have other friends with kids, so naively we attributed Noah's lack of speech to the fact that boys sometimes start talking later than girls. Then we came to realize something was not quite right.

Stephanie: What was it like wanting to communicate with and know your child's thoughts or ideas on things but not being able to?

David: In our world, we tend to take the importance of communicating for granted unless there's a problem in that area, that we don't realize how essential communication is to life, community, connection, and relationships.

Noah passionately pointed to the letters during the interview, which can be exhausting, to answer the questions.

Stephanie: Noah, what was school like for you without a way to communicate and not being intellectually engaged?

Noah: It was a waste of time, and that’s an understatement! It was babysitting, warehousing, and public kindergarten year after year after year. I was longing to learn, to be intellectually stimulated and challenged.

Noah then paused and asked his mom to explain feeding the brain. His mother explained that if the public school system cannot engage students who are non-speaking, they can at least engage the brain and give grade level material. Noah again voiced his opinion through the letter board, spelling out “presuming competence.”

Stephanie: What were Noah’s academics like from preschool on through 11th grade?

Nadine: He was unchallenged, bored, frustrated, and demeaned, in our opinion. While Noah’s SPEECH is impaired his LANGUAGE [what he understands] is not.

Noah said he wanted to add his thoughts about how educators and others view the behaviors of those on the autism spectrum.

Noah: If you were treated as “retarded” [Noah chose this word because this is how society makes him feel] 24/7 you would get bored, anxious, and angry. When I am intellectually engaged and challenged it helps me to not have what people call “behaviors.” The word *behavior* implies intention, when it is actually a fight-or-flight response to repeated, consistent underestimation of my abilities. My body control can be sketchy at best without the proper supports in place. The other key element, again, is presuming competence.

While Noah continued his thoughts, he verbally spoke the words “competence” and “key element” repeatedly.

Noah: Don’t speak to me like I am three or an animal, or talk over me, past me or about me right in front of me. Get past my exterior and believe the real me is stuck inside.

Noah and his parents advocated for the use of his communication method for his high school Individualized Education Program (IEP). One teacher believed in it and was becoming trained to allow Noah to use the letter board for academics, but when she transferred schools, training a new teacher was not embraced and the school found so-called research that said the methodology is pseudo-science and not evidence-based, so they refused to allow the training and admission of it in the IEP. Noah and his family decided to go another route. Noah was not interested in a special education diploma; he wanted a high school equivalency, to sit for the GED. Noah took a pre-test, participated in GED prep classes, and was deemed GED test ready! But Noah and the group of non-speaking students who hoped to be the first group of non-speaking students to take the GED were declined accommodations for the GED.

Stephanie: How did you feel, Noah, about not being able to take the GED? What is your goal or path now?

Noah: My dream is writing, presenting, and advocating for educating others. Not having a diploma won’t stop me, but I, like everyone else, deserve the chance to have objective measures to prove my intelligence and be allowed to pursue higher education if I so choose.

Stephanie: How do you feel when people judge you because you do not speak?

Noah: It enrages and disappoints me [and out loud said, “disappoints me”]. People are small-minded and can’t open themselves to the possibility of neurodiversity. My brain processing, my autism if you will, is magnificent. My brain controlling my motor movement or my body, not so much.

Stephanie: As a family, what are the thoughts you want to leave the readers about the importance of assistive and augmentative communication devices such as the letter board for non-speaking persons on the spectrum?

David and Nadine: We encourage the readers to have an open mind and heart as they consider the importance of having a voice. Your child has been locked in a silent prison long enough. As you explore and participate in this methodology, respect the process and progression. It is systematic for a reason from an emerging motor skill standpoint and from an emotional standpoint.

Don’t expect deep, meaningful conversations with your child in the beginning. It will take time, practice, consistency, commitment, but it’s worth it. And it’s imperative to learn from a trained, seasoned communication partner.

Noah: Everyone deserves a voice, even non-speaking individuals. I’m not looking for special treatment, just equal treatment.

Noah added he wants educators and the community to understand the importance of having a voice and its importance to connecting people. He wants people to consider how individuals who are different are treated, and not to judge people by their outside behaviors. He said he feels insulted that this form of communication is not considered real and that it insults the intelligence of those who are non-speaking who want what others want which is to express thoughts, feelings, and ideas and to be able to contribute to society in some way.

Noah: I want to speak to the fact that these words are coming from me—this communication is REAL. It has changed my trajectory, my future, and my life! My family’s too.

Noah Seback is a 20-year-old individual who happens to be a nonspeaking autistic. This is only part of his identity, but a defining one. Since learning to point to letters on a letter board to communicate he now has a voice which seeks to change the definition of that label. Noah resides in Atlanta, Georgia with his parents David and Nadine. Reach out to Noah at: <https://quirkthrives.com>