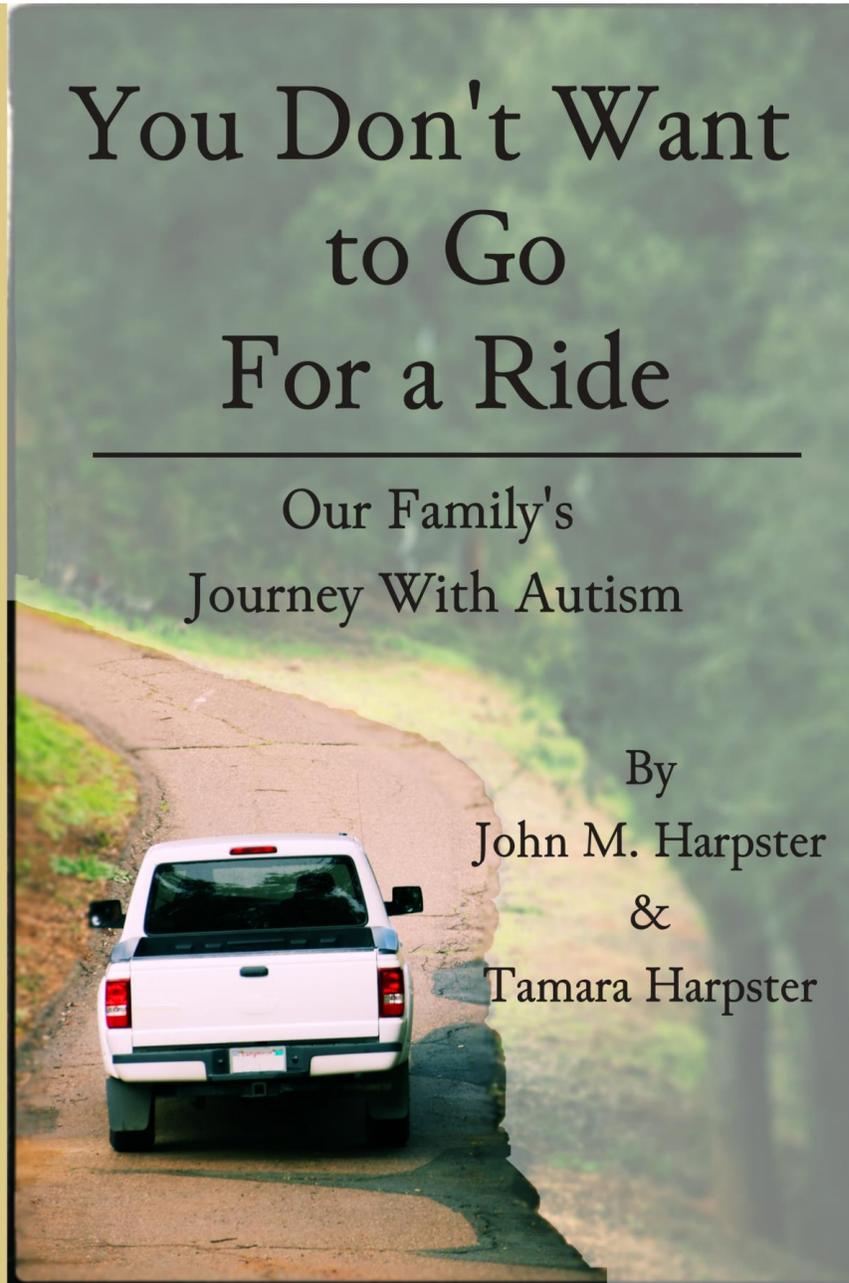


# You Don't Want to Go For a Ride

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Our Family's  
Journey With Autism

By  
John M. Harpster  
&  
Tamara Harpster



*Excerpts from*

*“You Don’t Want to Go for a Ride: Our Family’s Journey with  
Autism”*



*Excerpts from*

# "You Don't Want to Go For a Ride"

*Our Family's Journey with Autism*

JOHN M. HARPSTER

&

TAMARA HARPSTER

Shell Creek  
Publishing



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## *D e d i c a t i o n*

*I dedicate this book to my husband, whose example has helped me to be a better person, and to my son, John-John, who has been my teacher in so many ways over the years. I don't know what I would do without them.*

Tamara

*To my family, Tammy and J.T.*

John





## *I n t r o d u c t i o n*

After writing our book, I have met many other parents of autistic children who are searching for answers in their journey. I have assembled the last section of each chapter into this publication. The last part of each chapter was titled “Resources, References and Reflections” and contained a list of resources, references and thoughts about our experience with our son. I thought that others might find this list helpful, so I have gathered them into this publication and I’m providing it for other parents who may not have time to read the entire book. I hope that others find it helpful.

The website links were last checked in 2017 so some of them may be out of date or not exist as of November 2019.

Tamara S. Harpster



## *P a r e n t s   a n d   A u t i s m   C a u s e s*

In the years since I was pregnant with John-John, I have read many articles that gave theories on the causes of autism. I have also found that this search is controversial within the autistic community. An autism cure is questionable at best due to concerns about forcing adults to receive medication or therapy, or that parents will use tests to avoid having children with autism.

However, parents with non-verbal, violent children are quite interested in a cure in order to reduce the negative impacts on their child and their family. In my opinion, the current broad definition of autism causes differences of opinion between autistic people and parents. Based on the definition of autism within the Diagnostic and Statistical Manual of Mental Disorders, or DSM-5<sup>1</sup>, autism denotes the deficits with social communication and interaction. The severity can range from a verbal person who misunderstands many social situations to someone who cannot speak and is unable to read social cues. Spoken language is an important part of so many social situations that when a person is unable to speak, it can become challenging to try to find a different way to communicate. For parents who have not experienced autistic people, and whose only knowledge of the spectrum is from the movie *Rain Man*, the lack of verbal communication can seem like a brick wall between them and a relationship with their child. Parents may fear that their child will never be able to live on his or her own, go to school, fall in love or build a family of their own. This fear can drive them to try to solve the problem by attempting to make their child normal, since it is the only way they know how to relate to their children.

In addition, there are other conditions such as Attention Deficit Disorder (ADD), Attention Deficit Hyperactive Disorder (ADHD), epilepsy, Tourette's syndrome, fragile X syndrome (FXS), Sensory Processing Disorder (SPD), Obsessive Compulsive Disorder (OCD), and intellectual disability that can coexist with the communication difficulties of autism and cause additional issues in the autistic individual. Many individuals and families can learn to accept and deal with all of these problems, but it is extremely challenging and can cause a great deal of stress for everyone involved. When most of our society has families with children that

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<sup>1</sup> The Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Edition (DSM-5) is a manual used by psychiatrists for the diagnosis of mental disorders. In 1952 the manual was developed from statistical history and other sources to standardize psychiatric diagnosis. The number 5 refers to the version, in this case the fifth version of the DSM. Autism is one of the disorders defined and DSM-5 updated the diagnostic criteria for Autism in 2013. At that time, several separate diagnoses were combined into one set of criteria for a diagnosis of Autism Spectrum Disorder (ASD).

talk, and these families share stories about their children and their normal lives, the parents of an autistic child can feel very alone and may wish for a simpler life without all of the problems of the disorder.

For the autistic individual, all of these conditions are often viewed as a part of who they are and the core of the personality because they don't know any other way. To parents and family members, the conditions are viewed as obstacles to the relationship they envisioned with their child before the diagnosis. These two very different views of the same disorder lead to controversy and disagreement over whether autism should be cured or supported. The parents want a cure – not because they want to change their child, but because they want to get to know their child in the only way with which they are familiar. For autistic people, their communication problems, stimming<sup>2</sup>, anxiety and other elements of their lives are a part of them, and so a cure would mean that other people cannot love them as they are.

There are many theories about the causes of autism, but there is not yet a consensus on a single cause – or if there even is a single cause, due to the variety of people on the autism spectrum. The viewpoint has transitioned from seeing the cause of autism as a psychological disorder to seeing it as a disorder caused by genetics or environment. Society has moved away from pointing a finger at the parents for their behaviors to blaming the environmental contaminants or genetic background for causing autism. In turn, this has led to many researchers looking for a cause that can be prevented. The interest in finding this cause and a possible prevention of autism can be seen on the Internet with more than thirty-six million results from a Google search.

While this is an improvement for parents, autistic adults dislike that their condition is viewed as a disorder, when they feel that it is part of who they are and that some of the accompanying conditions are

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<sup>2</sup> Self-stimulatory behavior, also known as stimming and self-stimulation, is the repetition of physical movements, sounds, or repetitive movement of objects common in individuals with developmental disabilities, but most prevalent in people with autistic spectrum disorders. It is considered a way in which autistic people calm and stimulate themselves. Common stimming behaviors (sometimes called stims) include hand flapping, rocking, head banging, repeating noises or words, snapping fingers, and spinning objects. In the Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association, this type of behavior is listed as one of the symptoms of autism or "stereotyped and repetitive motor mannerisms".

Rosalind Bergemann (2013). *An Asperger Leader's Guide to Living and Leading Change*. Jessica Kingsley Publishers. ISBN 9780857008725.

Valerie Foley (2011). *The Autism Experience*. ReadHowYouWant.com. ISBN 9781458797285.

Stephen M. Edelson, Ph.D. "Self-Stimulatory Behavior". Autism Research Institute.

Temple Grandin, PhD (November–December 2011). "Why Do Kids with Autism Stim?". *Autism Digest*. Retrieved 25 March 2014.

Eileen Bailey (27 August 2012). "Stimming". Health Central. Retrieved 25 March 2014.

"Stimming: What autistic people do to feel calmer". BBC. 5 June 2013. Retrieved 25 March 2014.

"Autism Spectrum Disorders", 1994, Diagnostic and Statistical Manual, American Psychiatric Association

strengths instead of weaknesses. However, due to the early studies and documentation about autism, a strong negative view still exists in the general populace, as well as an equally strong feeling that autism is something that should always be prevented. The neurodiversity movement has grown, comprised of autistic adults and others with disabilities who seek acceptance of the condition instead of trying to eradicate it. In the meantime, many parents are interested in possible causes and prevention of autism due to the association of difficult behavior and problems in obtaining adequate support for children with the condition.

As someone in the middle of this discussion, I see points on both sides, while being concerned about trying to change autistic behaviors in order to fit a cultural definition of normalcy. I would like to see both sides meet in the middle, where help is provided in communication while recognizing the strengths of an autistic person.

Over the years, I have read about autism and the possible causes as part of my mourning over the family I thought we would have. There was a part of me that felt if I could find something to blame for the difficulties with our son, then the problems could somehow be fixed. I also had to work through my own self-blame and the choices I made that might have made things worse, and life more difficult for him and our family.

For example, as part of my research, I learned that our family shows several areas that may have contributed to an increased likelihood of an autistic child. In our case, one item was John's age as a father. When I gave birth to our son, John had just turned 41. Studies have shown that the risk of autism increases as the father gets older (i.e. above the age of 35 at the time of conception). Since the earliest known study regarding this risk wasn't performed until 1995, we were completely unaware of the increased potential for autism when John-John was born.

The other risk factor comes from my side of the family, many of whom are introverted. Both sides of my family have a strong interest in the scientific fields as well. This has also been linked to higher autism rates. During my research for this book I have come to feel that I am an undiagnosed female with what was known as Asperger's Syndrome<sup>3</sup>. With these factors and based on current research, John and I had a strong chance of having a child with autism.

The following is a short list of current theories and research in this area. I've included these references because I remember my early search when I was trying to understand what happened and if there was a

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<sup>3</sup> In the USA, the term Asperger's Syndrome is no longer used in diagnosis and the term Autism Spectrum Disorder (ASD) is now used in the latest edition of the DSM-5. Other countries still use the term Asperger's Syndrome and differentiate it from classical autism. The primary difference between Asperger's Syndrome and classical autism is speech abilities. Children diagnosed with Asperger's Syndrome develop language normally and primarily have issues in reading social cues. Children with classical autism are delayed in speech or do not develop speech in addition to their issues in reading social cues.

possibility of having more children with autism. However, this is not an exhaustive list of the causes, and continuing research may refute these ideas in the future, just as the psychological model was overturned. I will also add that there are families who show none of the more solidly supported risk factors for an autistic child who have one, so there is no guarantee that autism will not affect your child. As the years pass, I find it more productive to focus on the strengths of my son, support working through his weaknesses and love him for who he is – not who I wanted him to be. Reviewing the possible causes can help in the grieving process of the loss of the child a parent envisioned, but I don't recommend that the search replace working with and loving the child you have.

Andersson, O. et al. "Effect Of Delayed Versus Early Umbilical Cord Clamping On Neonatal Outcomes and Iron Status at 4 Months: A Randomised Controlled Trial". *BMJ* 343.nov15 1 (2011): d7157-d7157. Web. 23 Mar. 2016.

Carnegie Mellon University. "Genetic risk for autism stems mostly from common genes." ScienceDaily. ScienceDaily, 20 July 2014.

"Key Findings: Population Attributable Fractions for Three Perinatal Risk Factors for Autism Spectrum Disorders, 2002 and 2008 Autism and Developmental Disabilities Monitoring Network". *CDC – Centers for Disease Control and Prevention*. N.p., 2014. Web. 23 Mar. 2016.

Schieve, Laura A. et al. "Population Attributable Fractions for Three Perinatal Risk Factors for Autism Spectrum Disorders, 2002 and 2008 Autism and Developmental Disabilities Monitoring Network." *Annals of epidemiology* 24.4 (2014): 260–266. PMC. Web. 23 Mar. 2016.

Silberman, Steve. "Neurotribes: The Legacy of Autism and the Future of Neurodiversity". 6th ed. New York: Penguin Random House LLC, 2015. Print.

Wang, Sam. "How to Think About the Risk of Autism". *New York Times* 2015: SR6, New York Edition. Web. 29 Mar. 2014.

## *Pregnancy and Birth*

Based on my experiences with my birth and the mental illness I had, I wanted to share resources for other mothers who may be experiencing similar feelings. If the mother is disappointed with her birth experience, no matter what kind of experience she has, she should receive help and support. Many mothers are satisfied with their birth, but for those dealing with depression, anxiety or trauma, some of the resources may aid in finding someone to talk to. Focusing only on physical health ignores the impact that depression, anxiety and trauma can have on the child and the family.

Another reason for this section is my husband asked me if I thought the delay in the delivery of John-John might have contributed to his autism. After many years of thinking about this question, I mostly believe that he would have been autistic no matter what. However, a part of me thinks I did something during my pregnancy – or the delivery – to cause his problems.

After several days of attempting an active labor, I finally had a cesarean section. While growing up, I was often teased and called a boy. Even when I reached college age, I would be called sir and I did not get calls or attention from the young men around me. I lacked self-confidence that I was fully a woman, so it was very important to me to be able to give birth as naturally as possible. I also knew that cesareans involved open abdominal surgery that could lead to complications and poor outcomes for the mother and baby. I felt very strongly that there was a “right” way to have a child and that it did not involve epidurals, episiotomies, confinement to a bed or other interventions. However, because of my low self-esteem and lack of confidence, I did not voice my innermost beliefs, even when I noticed that events had happened that I did not entirely agree with.

I spent several days in the hospital with stalled labor, in spite of the medications the staff had administered. Since they dosed me with a Pitocin drip, I was unable to walk or get much sleep. They also did not allow me to eat during that time because of the possibility of vomiting during surgery. A monitor showed John-John's heartbeat as normal and steady, except when my labor picked up the pace. Based on what I learned later, since he was pushed up against my pelvic bone, the increased contractions would have caused fetal stress and a lower heartbeat. My attempt at labor certainly lasted much longer than is usually allowed in the U.S., but I knew from my family history that lengthy labors were normal, so I didn't think it was that unusual.

Three days after I entered the hospital, I finally accepted the fact that I would not be able to deliver my son on my own and would have to undergo a caesarean section. The memory of that moment still hurts, and I wept bitterly while John held me. It hurt even more when I read my medical record, which merely stated that I was "tearful," with no mention or importance given to my mental state or the sense of failure I would experience from this decision. Later on, I added to my guilt by remembering that some studies show a link between cesareans and an increase in autism diagnoses.

During John-John's early years, an autism diagnosis was considered a grim outcome. I beat myself up for my lack of will and action during the pregnancy and birth process. I have also wondered if my lack of treatment for depression during his first few years contributed to how he turned out. One school of thought tells me that genetics and environmental influences are the main causes, but a part of me does feel a level of guilt – this in spite of Dr. Bernard Rimland's attack of the "refrigerator mother theory"<sup>4</sup> and later research that also points to genetics as the cause of autism.

After many years of blaming myself for my decisions, I had to decide that even if my actions did cause his autism, I can't go back and change what happened. However, I can change how I act today, so I work to better myself and help my son. Based on my struggles, I want to encourage parents who are depressed to seek help for themselves. I took many years to learn the lesson that if I want to take care of others, I must first take care of myself so I don't fail them at a critical point. Don't be ashamed to ask for help and don't be afraid to push for that assistance when others tell you that a problem "isn't that big a deal." To those who know a parent who is depressed, don't be afraid to speak up and let them know you support them. Part of the reason I finally sought treatment was due to my husband's backing and acceptance of me. If I had not had that extra little push, it might have been much longer before I sought help – if I ever realized that I needed help at all.

In the end, the parents and the child must live with the choices made for their family—not the doctors, not the therapists, not the teachers, and not the friends or family who invariably offer their well-meaning advice. However, at the end of the day, when the door finally closes and all the advice-givers leave you with

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<sup>4</sup> When Dr. Leo Kanner performed research in 1943 studying autism, he noted that mothers and fathers seemed to lack warmth towards children exhibiting autistic characteristics. In the 1950s and '60s, Dr. Bruno Bettelheim formally proposed the Refrigerator Mother theory, which was widely accepted by medical experts and the public at the time. In 1964, Dr. Bernard Rimland published *Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behavior*, which attacked the Refrigerator Mother hypothesis. Dr. Bettelheim then published *The Empty Fortress: Infantile Autism and the Birth of Self*, where he compared autism to being a prisoner in a concentration camp with the implication that the parents were the guards and the child the prisoner. Parents of autistic children spoke out against the theory in the 1960s and pushed back against the belief that autistic children had been abused. Dr. Kanner eventually spoke out against the Refrigerator Mother theory and the theory has been widely discarded in the US; however, France and South Korea still believe in this mindset. The current theory is that autism is caused by genetics and is a physical difference instead of an emotional disorder caused by poor parenting.

your thoughts, the parents and their child will have to live with the behavior and consequences that result from their decisions. I also came to the realization that while I could have taken actions that may have made things better, those acts might very well have made the situation much worse. I did the best I could with what I knew at the time and that will simply have to do.

In the years since John-John's delivery, there continue to be changes and improvements in the birthing process. Even with these resources available, a first-time mother can easily be intimidated by the overwhelming responsibility she feels to nurture a healthy baby. There are many resources for women who are depressed or grieving after their birthing experience, they can still obtain more help than they are currently receiving. These resources are available on the Internet and they look to be quite supportive, so I encourage mothers who feel that they are experiencing depression to seek help as soon as possible. This includes reaching out to your partner, family or friends if you need support to ask for medical help. I know that John's strength made a difference when I sought help for myself.

### **Postpartum Depression and Birth Trauma**

Over the years, studies have shown that many women experience significant depression after childbirth. These symptoms can include feelings of anger, lack of interest in the baby, crying and sadness, and possible thoughts of harming baby or self. Postpartum depression lasts well beyond the typical "baby blues" period that occurs for about a week or so after the birth. Also, a new disorder called birth trauma has displayed characteristics common to post-traumatic stress disorder, or PTSD. In both cases, the mother does not function rationally, and as a result needs help and support. I speak from experience when I talk about not thinking rationally, and I know that these mental illnesses can affect the care of the newborn and any other children in the family.

Both post-partum depression and birth trauma can be difficult for parents to talk about, because there is an expectation in US culture that there is a quick recovery from childbirth. Medical professionals may not have the requisite experience in recognizing the signs of depression and trauma. Family and friends who do not have personal knowledge of depression or trauma may not understand how the birth experience can affect the mother, and so are unable to provide help or support. This leaves the mother feeling isolated and unable to move on from the birth experience. While my research points to mothers as the most affected, the birth affects the father and other children as well, so their feelings should not be discounted. The goal should always be to support the family so that everyone is cared for. If the parents receive support and understanding, they will be better able to take care of the new baby.

Support groups can help mothers and fathers so they don't have to deal with these issues on their own. In addition to the resources I have included, I recommend that parents search for their own solutions for the help they need.

### **Childbirth Loss**

After my birth experience, I searched for books that helped explain why I felt so badly about what had happened. I found a few that were written with an angry view point, which validated my feelings but did not help me deal with my anger at what I felt I had lost. The only book I found helpful at the time dealt with mourning losses at childbirth. *Ended Beginnings: Healing Childbearing Losses* provided a sympathetic view with ideas on how to mourn and move on after a loss. The focus is on miscarriages, stillbirths and infant deaths, with mention of other types of loss. I found it very helpful. In my opinion, mothers should be allowed to grieve for the loss of their ideal childbirth so they can let go of the bad experience and move on. Childbirth losses should not be a contest to see who suffered the most horribly, but instead should recognize that each mother needs to express and recognize her feelings so she can better deal with them and find her own personal solution.

### **Non-Medical View of Birth**

The resources in this section focus on a non-medical focused method of birthing. All of the resources recognize the importance of modern medicine in healthy births but also look beyond to some of the mental and spiritual aspects of the mother and the family. I recommend the following books, authors and websites:

Ina May Gaskin is the founder and director of the Farm Midwifery Center. She advocates for positive birth experiences for all women. She has been a midwife since 1971 and has participated in more than 1,200 births. Her center is noted for its low rates of intervention and low mortality rates. She has also contributed to several books for childbirth.

La Leche League International is a group that supports breastfeeding. Mothers can connect with each other at the monthly group meetings, which are run by volunteer leaders who have breastfeeding experience. I know that some women have had negative experiences with groups, but I found their meetings helpful and healing. It was refreshing to see other women with babies and toddlers dealing with some of the same issues I did while I tried to figure out how to be a mother. They also sell many good titles on their website. A toll-free number is available 24 hours a day for questions about breastfeeding. I served as a leader many years ago and I took a nighttime shift for the help line. There may also be a local leader you can call. All leaders are

accredited by La Leche League and receive training before they can begin helping mothers. See the reference for La Leche League for more information on how to contact them and their leadership program.

Michel Odent – French obstetrician who set up a clinic focusing on a supportive environment for women nearing childbirth. *Birth Reborn* contains beautiful pictures of women laboring and giving birth. I found these images very powerful and empowering, but be prepared for viewing the human body in its natural form.

Bettelheim, Bruno. *The Empty Fortress*. New York: Free Press, 1967. Print.

"Birth Trauma Association / Helping People Traumatized By Childbirth". *Birthtraumaassociation.org.uk*. N.p., 2016. Web. 23 Mar. 2016.

Gaskin, Ina May. "Home Page". *Ina May Gaskin*. N.p., 2016. Web. 23 Mar. 2016.

Griebenow, Jennifer Jamison. "Healing the Trauma: Entering Motherhood with Post-Traumatic Stress Disorder (PTSD)". *Midwifery Today* 2006. Web.

Kluchar, Jodi. "Did You Have A Traumatic Birth Experience?" *Post-Traumatic Stress Disorder After Childbirth*. N.p., 2016. Web. 23 Mar. 2016.

"LLLI / Home". La Leche League International. N.p., 2016. Web. 23 Mar. 2016.

La Leche League International Website - <http://www.llli.org/>

La Leche League USA Website and group locator - <http://www.lllusa.org/locator/>. Call 877-452-4324 for more information or email to [info@lllusa.org](mailto:info@lllusa.org).

La Leche League Leadership - <http://www.llli.org/lad/talll/talll.html> - Resources about the accreditation process for a La Leche League Leader.

Leboyer, Frédérick. *Birth without Violence*. New York: Knopf, 1975. Print.

Odent, Michel. (May 12, 1984) *Birth Reborn*. Westminster, Maryland. Pantheon.

Panuthos, Claudia, and Catherine Romeo. *Ended Beginnings*. South Hadley, Mass.: Bergin & Garvey Publishers, 1984. Print.

Rimland, Bernard. *Infantile Autism*. [New York]: Appleton-Century-Crofts, 1964. Print.

## *Signs of Autism in Toddlers*

Looking back at John-John's toddler years, I remember feeling uneasy about some of his behaviors, but pushing back my worries and figuring that I was just an over-protective first-time mother and that my son was probably normal. I can also see that it was easy to interpret his acts as bad behavior, when it was more likely that most of it was caused by his difficulties in communicating and understanding the rules of the normal world. The move to Wyoming removed many stresses on our family, but I was still concerned about appearing normal and having my child behave. Based on what I have learned in the last year, I wish I had known that some of his behaviors were probably the result of his inability to understand us and his attempt to make sense of the world. I also think there was and is a mischievous side to my son, and that some behaviors were just him acting out to test the limits of what he could and could not do. The problem is to try to figure out which behavior is which, so that firmness and understanding are used in the right combination. Too much firmness can lead to anxiety and uncertainty in the child, but too much understanding can lead to inappropriate behavior. It is a difficult balancing act for any parent and more so for a parent of an autistic child, due to the communication issues.

I can also see that there were signs of my son's problems long before we heard a diagnosis of autism. In most cases, I think parents should trust their gut instincts about their child. They are around their child most of the time and professionals sometimes downplay parents' concerns as over-protectiveness. While there are parents who do not have the right skills or who need help in parenting, I believe that many parents should trust themselves more and look at what is right for their family, not what is considered right for the average family – or worse, what's easier for the professional to deal with. Early intervention can help autistic children learn to interact with the world sooner and it can be important to get the additional help that might make a difference for that child. However, I also believe that children continue to change, so that even if some of the early opportunities are missed, the child will not stop completely in their development.

For parents who are feeling a bit uneasy or unsure, autism research has revealed that early intervention can help in reaching children on the spectrum. A checklist of behaviors was created in order to help find possible autism at earlier ages than in the past. A study has shown that the use of a checklist at 18 months or

younger can identify autism or other developmental delays.<sup>2</sup> When John-John was a toddler, diagnosis usually didn't occur until a child was three or older. Now it takes place at two years of age or younger. This early diagnosis can be used to increase interaction with the child and improve their ability to communicate verbally. However, in some cases, there are physical issues with verbal communication, so other methods of communication should be explored with the child. It is likely that the child is trying to communicate with the parents, but it may be subtle and non-verbal, and very difficult to detect. With computers and various other media, there are many more options available for working with a child on their communication skills.

"Assessment & Diagnosis" *Autism Research Institute*. N.p., 2016. Web. 24 Mar. 2016.

Fernell, Elisabeth, Mats Anders Eriksson, and Christopher Gillberg. "Early Diagnosis of Autism and Impact on Prognosis: A Narrative Review" *Clinical Epidemiology* 5 (2013): 33–43. *PMC*. Web. 24 Mar. 2016.

"Screening And Diagnosis" *CDC – Facts about Autism Spectrum Disorders – NCBDDD*. N.p., 2015. Web. 24 Mar. 2016.

"What Is Autism? Autism Science Foundation" *Autism Science Foundation*. N.p., 2015. Web. 24 Mar. 2016.

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<sup>2</sup> *Validation of the Infant-Toddler Checklist as a Broadband Screener for Autism Spectrum Disorders from 9 to 24 Months of Age*,

Amy M. Wetherby, Susan Brosnam-Maddox, Vickie Peace and Laura Newton, *Autism*, September 2008

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2663025/?tool=pubmed>

## *Parental Support for Autism*

When John-John was a toddler, we did not yet have a diagnosis for autism, but John and I were coming to grips with the fact that our son was not like other children. I remember grieving as the reality sank in and I realized that he had a disability that did not show up until he was older. I was oddly envious of parents who know of a disability when their child is born. During John-John's first few years, there were many frustrations, which is normal for any parent, but also a feeling that he would eventually grow out of these behaviors. With a diagnosis of autism and the grim outcomes of the time, it felt like I had been living a lie and that there was little hope for our son to have a normal life. I resisted this idea and I did not want to accept that my son would eventually need to be put into an institution, hidden away from the world. I knew that some parents had started taking care of disabled children at home, such as children with Down syndrome, so I felt that we could do something to help him.

When we tried to work with the pre-school, part of me hoped that there would be an easy solution and our son would be helped and become a normal child. But a part of me mistrusted professionals in this field. I wanted to believe that there was a fix, but in the end I felt that my husband and I knew as much or more, and could do more, for John-John on our own.

I would experience great difficulty in choosing a different path due to my mistrust, anxiety and lack of confidence when working with institutions and their rules. I felt I needed to be a strong advocate for my son, but I also knew that I would back down and not speak up in direct confrontations. I do not react quickly in confrontational situations and I still have problems with speaking up about problems as they occur. If there had been better and additional choices in the pre-school community at the time, perhaps we could have found a match for our situation. But we did not have the resources to work with. I began researching autism at this point, doing my best to find positive outcomes, but it took several months for me to dig out any real content in our local library and the little research I could find on-line at the time.

While there now exists a greater understanding of autism, it can be overwhelming because there are so many choices. A stigma still hangs over autism and the portrayal of a grim outcome for the children if they aren't helped. In my opinion, the movie *Rain Man* helped with autism awareness, but the ending enforced the idea that autistic people will eventually be institutionalized. There are many therapies for early intervention, depending on the people parents work with when their child is diagnosed. The interventions can consist of speech therapy, assisted behavioral analysis (ABA) therapy, relationship development

intervention (RDI) therapy, and occupational therapy. A parent can visit with professionals and have choices for therapy to help reach their child. There are also more positive images in the media, including the movie about *Temple Grandin*, *Life, Animated* and *Po*. As I write this book, *Sesame Street* has added an autistic character and other movies, such as the *Power Rangers* have announced that they will include an autistic character as one of the rangers.

However, all of these treatments cost money, and parents must try to gain financial aid through their health insurance or state agencies. In the meantime, they still have to deal with the behavior of their child and may have to endure months on a waiting list before they receive any help. Respite care for parents is available, but may be limited or not meet their needs. Assessing and choosing from among these options can be challenging and add the stress of feeling that the wrong choices may doom the child to a lifetime of solitude in their own world.

In addition, the current resources from state agencies, schools and insurance are scarce, and parents must sometimes be willing to become warriors to obtain adequate support for their situation. There can also be a great deal of pressure to accept a solution that works for the agencies, but which causes additional stress in the family because of how the child is treated.

Parents have to deal with their feelings about their dreams for their child and how those dreams have to change. To me, this period resembles mourning for the child they thought they wanted and might feel that they have lost. Based on my experiences, the parents should also look for support and help as they work through their feelings about not having the normal child they expected. It might help to understand that parents of normal children also need help from time to time when their child runs into difficulties. Parenting children to be responsible adults is a tough task for anyone and problems that seem huge when a child is a toddler or preschooler can change as the child grows.

I have found a list of resources from parents and groups that may help as they try to figure out what autism is and how it will affect their family. I wish that I had been able to find some support from a parenting group so that I would have known our family was not alone with our issues.

Asperger Syndrome & High Functioning Autism Association – [www.ahany.org](http://www.ahany.org)

Autism Highway – [www.autismhwy.com](http://www.autismhwy.com)

Autism New Jersey. Autism New Jersey. n.d. 2 October 2015. [www.autismnj.org](http://www.autismnj.org).

Autism Research Institute. n.d. 2 October 2015. [www.autism.com](http://www.autism.com)

"Autism Through the LifeSpan." *Autism Society*<sup>3</sup>, n.d. Web. 2 October 2015. <http://www.autism-society.org/living-with-autism/autism-through-the-lifespan/>

Disability Scoop. n.d. 2 October 2015. [www.disabilityscoop.com](http://www.disabilityscoop.com)

Meetup.com – <http://www.meetup.com/> – search for local support groups for autism.

"Resource Guide." *Autism Speaks*<sup>4</sup>. n.d. 2 October 2015. <https://www.autismspeaks.org/family-services/resource-guide>

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<sup>3</sup> The Autism Society is one of the oldest support organizations for autism. It was founded by Bernard Rimland, a researcher of autism and parent of an autistic son.

<sup>4</sup> The Autism Speaks organization does not have a good reputation with autistic adults however many families feel they have received help and support so I am including a reference for families looking for help.

## *L e a r n i n g   A b o u t   A u t i s m*

As John and I adjusted to the reality of our son's autism, I renewed my research skills. I read as much as I could about the condition, looking for bits and pieces of hope that my son could eventually lead an independent life. In the meantime, we began to adjust to the fact that his meltdowns, humming and other odd behavior would not go away easily. However, a part of me still felt that if I did the right things, my son would respond and somehow become a normal child. I knew there was a person in there, and I just wanted to talk with him and learn more about what he liked. I wanted to share holidays with him and create good memories that he could look back on as he grew older. I had accepted this part of our new life, but I couldn't concede the entire situation as hopeless. I vowed that I would fight for him to get the most he could out of life.

I wish I had been able to find other parents to share experiences. I did attend a mother's group a couple of times, but I felt very disconnected from what the other mothers were sharing that I just couldn't continue. They told stories of their problems with potty-training, their child saying "no" and talking nonstop, or making messes. I had a child who I couldn't talk with, who showed no interest in potty-training, and who would run back and forth through the house and hum to himself instead of playing. I felt such a disconnect from other families that I felt isolated and out of place, so I stopped attending the meetings. It would have helped if other parents of autistic children were available to talk to and share stories.

I would have talked about how, after several months, I had learned that my son only wanted to wear green or blue shirts. Any other color would result in a tantrum – and I had no idea why. It took me a few months to figure that one out. Eventually, I was able to buy a bunch of green, blue and green-mixed-with-blue shirts that he could wear without screaming or throwing a tantrum. He wouldn't eat bananas, a fruit most babies love, but he would make a concoction of apple juice, milk and water and drink that right down. I definitely recommend that parents who are new to the diagnosis of autism seek out other parents of autistic children so they can share their experiences. Online blogs and forums are available so you can find out more information from parents who understand the challenges of raising an autistic child.

As our family gradually accepted the diagnosis of autism, we found our way of life changing. We learned to deal with unusual behavior and coped with the issues as they came up. The following links describe life with an autistic child. While it's not what parents expect, it can be rewarding even when things are most

challenging. I would encourage parents to always look for the positive behaviors in their child. It is much too easy to focus on the negative aspects.

"6 Benefits to Having an Autistic Child." *Scary Mommy*. N.d. October 26, 2015.

<http://www.scarymommy.com/the-perks-of-autism/>.

"I'm Not Sorry." *Huffington Post*. January 23, 2014. [http://www.huffingtonpost.com/courtney-alison/im-not-sorry\\_b\\_4599233.html?utm\\_hp\\_ref=mostpopular](http://www.huffingtonpost.com/courtney-alison/im-not-sorry_b_4599233.html?utm_hp_ref=mostpopular).

"Let's Talk Parenting Taboos." *TED Talks*. December 2010.

[http://new.ted.com/talks/rufus\\_griscom\\_alisa\\_volkman\\_let\\_s\\_talk\\_parenting\\_taboos](http://new.ted.com/talks/rufus_griscom_alisa_volkman_let_s_talk_parenting_taboos).

*Speaking of Autism*. n.d. Web. <http://www.speakingofautism.com/>.

"Superman is Autistic." *Autism Sparkles*. June 30, 2013. October 26, 2015.

<http://autismsparkles.com/2013/06/30/superman-is-autistic/>.

"The Perks to Having an Autistic Teen." *Scary Mommy*. n.d. October 26, 2015.

<http://www.scarymommy.com/the-perks-to-having-an-autistic-teen/>.

## *A l t e r n a t e   C o m m u n i c a t i o n*

Many autistic children struggle with verbal language, but speech therapy can help. However, I have found that just because a child can talk doesn't mean they are communicating. Even as John-John has gotten older, I have had to step back at times and adjust my communication with him. I cannot rely on just interpreting his words. I also need to read his body language, his facial expression and his mannerisms while he talks. When he says, "I don't want to go!" at the top of his lungs and while running back and forth, I can interpret that as meaning he does not want to go somewhere. If he says, "I don't want to go" in a normal tone while standing still in front of me and looking at me, it usually means he does want to go, but is not sure if I will say yes. Communication includes speech, body language and cultural assumptions that frame the context of conversations. In addition, for most people, there is a commonality in how people view things, so there is a shared thought process. This is apparent when certain jokes are shared about men and women, or when people talk about the current television shows or world events. Autistic people aren't always plugged into these common thinking patterns and may appear uninterested in normal conversation. When there are problems with speaking or reading body language, the body language and speech of autistic people may make them seem distance or remote, when they are actually very interested in the subject.

With electronic devices, some of these hurdles can be overcome, but again, speech or typing should not be considered complete communication. Think of the misunderstandings that can occur in e-mailing between two people where there is only text without the accompanying body language that frames a conversation. There can also be cultural differences – even within the same country – that can cause a misinterpretation of statements that seemed benign to the speaker.

Based on my experience, I think it helps if the parents can be flexible and focus on finding a way for the child to communicate how they feel, what items they want and what they need to feel comfortable. When John-John was younger, I was a lot less flexible. I expected him to tell me his needs and what he wanted. As I grew older, I had to learn to be more adaptable and reach more into his world, instead of expecting him to always figure out how to operate in mine. I have also built experience in understanding more of John-John's context and thinking patterns, so that I can translate them and try to understand him better. I find myself seeing him more as a person with his own thoughts and ideas, and less as a child that has to constantly be told how he should act and behave. This is how I act with other adults, accepting their differences just as they accept mine, and I have seen – in my opinion – that this is a more mature approach that yields better results.

When John-John was four years old and I was still struggling to reach him, I began to realize that I also think in pictures and images. Over the years, I have remembered incidents from my childhood when I realized I didn't think quite the same way as other children. One time in class, I pictured the knowledge coming into my brain, like boxes of cargo that were loaded onto a conveyor belt and were somehow moved into the space. As I sat in class, I smiled as I thought this and I drew a doorway on the side of my head with my finger. I then pictured the boxes moving into my head, with all of the knowledge from the books and the teacher talking to the class. Then I looked up, saw the teacher and other children looking at me strangely as I moved my hands around. So I stopped and looked down, ashamed that I was acting different again.

As an adult, I realized that I translate speech into thought patterns and vice-versa in order to carry on a conversation. This realization is part of why I feel that I am on the autistic spectrum. After so many years, it's mostly automatic, but when I'm overly tired or talking about new things, I have to focus or I lose my place and stutter, or just get stuck. If I'm near even a small group of people, I won't talk at all, because it's less embarrassing than stuttering or freezing up. If I am talking about a subject I'm not familiar with, there is a slight delay as I translate, which usually leads to a slight delay before I can respond. Since conversations can move from topic to topic very quickly, I find it very difficult to interact and keep up without breaking the rhythm of the group. This is another situation where I find it easier to stay quiet instead of feeling foolish or out of place – when I respond to statements that others have already moved away from.

Over the years, I have come up with a visualization of what it's like to try to communicate with someone who thinks in pictures, like my son or myself<sup>5</sup>. My memory is filled with images and movies of the world around me. This media has words associated with them that I can repeat when communicating with others – like assigning a value or a title to the image. The more comfortable I am with the process, the easier the words flow, but when I talk about new things, I fall back on memorized phrases to communicate my feelings. At times it is difficult to keep things short, because I have an entire movie that I want to describe, complete with sound, images, feelings, colors and smells, while most people only want to hear a sentence or two. I think it is similar to someone trying to tell of the entire plotline of a Shakespearean play in a 140-character Twitter post. It can be done, but a lot of information will be missing.

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<sup>5</sup> John and I talked over this section and he did not understand what I was trying to communicate, which is an example of my problem. He told me that I should sum up my thinking as follows: “You have what you want to say in your mind in pictures, and it is hard to translate that into a language that other people understand.” I wanted to include his concise summary to help others who are trying to translate my description above.: - )

In order to overcome this difficulty and attempt to converse in a shortened form with others, I tend to use many quotes in my communication. I'll have a complete image in my head of a concept, with pictures, feelings, sound and a time component, but when I try to describe what I am thinking, most people become bored—or worse, annoyed or angry. In order to communicate all of my thoughts, I need to repeat a lengthy monologue, while most people can share experiences with a sentence or two along with common thought patterns. The other problem I have is that I don't seem to have the same view of the world as other people. I will leave out portions of a description that seem obvious to me, while over-explaining other sections that people take for granted.

When I find a quote that summarizes my feelings, it is a real time-saver for my communications. While I researched autism, I discovered the term "scripting."<sup>5</sup> This is a very accurate depiction of how I take shortcuts in speaking with others. It's much easier to have a set of memorized phrases to fall back on, instead of continually trying to come up with new words. For example, when my son was 8 or 9 he became fascinated with a story about a person who had tied balloons to a lawn chair and accidentally rose to the altitude of 15,000 feet when he untied his chair from the ground. For months, John-John would go around repeating the phrase "Lawn chair Larry" and giggling with delight about this odd story.

Until a friend pointed this out to me, I was oblivious to the impression it gave. I came across as a know-it-all, when all I really tried to do was use it as a shortcut or to back up my ideas, because people really didn't want to listen to my monologues. However, as a result of this feedback about using quotes, I'm now self-conscious when I use them. This adds to my anxiety level when communicating with others. I'm already apprehensive, because I don't read behavioral cues or body language the same way as others. I have learned to cope, but I pay a price with anxiety, overthinking social situations on and a reduced interest in communicating—unless I'm sure I can trust the other person. At some point, it might be interesting to try to

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<sup>5</sup> There are two types of scripting: echololia and social. Echololia scripting is the repetition of phrases that may or may not fit in with the current conversation. The quotes are direct from movies, cartoons, songs or other media and are repeated in order to have a way to engage verbally with others, and to provide comfort to the person using them. In this way, the scripting is similar to stimming. Social scripting is when the autistic person uses a set of phrases or quotes that they can repeat for certain specific situations and reduce their anxiety of having to come up with a response on the fly. The aim of this type of scripting is to increase the range of engagement with other people in ways that are more socially acceptable. Unfortunately, the repetition or quotes can appear rude or annoying, and is frowned upon by many non-autistic people. When autistic people realize that they are annoying other people, this can raise their anxiety level, which can then increase the amount of scripting used by the person. In this video, the young, autistic woman, Amythest Schaber, explains the two types of scripting. It was interesting to note the same types of pauses in her speech that I have when I am talking about some new topic or talking with someone who I don't know. <https://youtu.be/vtbbmeyh5rk..>

capture in a book the various rules I've developed over my life. But I don't know that I have enough time left on this earth to complete that type of endeavor.

Now that I know about the possible impression quotes can give, I've added an "internal check" before I speak. This is a validation of what my immediate future behavior will be. Before I speak or act, I quickly run through previous situations in my mind to determine what I should say, what tone of voice is acceptable, and what body language I should portray. Is the other person showing signs of boredom, lack of interest, hostility, anger or frustration, or some other emotion that could cause the encounter to escalate in emotional intensity? After many years of this, the check is normally pretty quick, but I still experience some delay in response to new situations, and I am sometimes annoyed with myself for missing some piece of communication from the other person.

When I was younger, I had a much shorter set of internal checks, and I annoyed, frustrated, baffled and angered people much more easily. I now have a longer set of internal checks, but my memory is not perfect and my checks do not cover every situation that could come up when dealing with other people. Because of the negative interactions I have had in the past, up to the point of driving away people who I cared about, I find that I prefer to not interact in most social situations, unless I have to or I am very comfortable with the people and trust that they will show patience when dealing with my social slips. After social situations, especially if they have been lengthy and I am tired, I will review the situation in order to see where I overstepped or misinterpreted behavior in order to add another internal check for the future. In the last year or so, I have started to move away from this model because of the level of anxiety and fear for social situations. I have been helped by having a stable situation for the last few years, a set of friends who are mostly understanding and tolerant, and the ability to control the times when I have to be involved in these situations.

As an example, while writing this section, I pulled up a memory clip of being introduced to someone. The clip involves a scene with me approaching the person I am meeting. I see a generic person who I am walking toward in order to shake hands and introduce myself. As I approach, I retrieve additional pictures of other interactions and I assess the stance of the person: how they are dressed, whether an arm is coming up for a handshake, is the person smiling, are they looking me in the face or are they looking away? As they shake my hand and tell me their name, I focus on repeating my name while shaking their hand without grabbing too tightly and not holding on for too long, then backing away to an acceptable social distance. Because of the other inputs involved with body language, I now focus on repeating the name to remember it

and also associate it with the face. I also work on imprinting the face in my long-term memory, because some faces blur for me and it is hard for me to make out that person later. Other faces are very distinct and I have no problem remembering those people later, although I may not remember their name. I repeat the name and the memory of the face so if I meet the same person again at the event, I have a better chance of using the right name. If I meet a person who reaches out for a hug, I realize a slight delay while I process the difference and decide whether I want to accept. Because I am not very sure of what is proper behavior, it is likely that I would accept the hug because I don't want to offend, even if I feel uncomfortable with that behavior. If I do hug the person, I monitor the situation to make sure I break the hug before it gets uncomfortable while trying to not break too soon. Most of the time I like hugs with people I know but I am still unsure of the proper protocol and I have to monitor my actions.

Because of my experience at the motel, I may try to engage the person by asking where they are from, what is their job, or do they have a family, depending on the type of event. Once I gain a piece of information, I try to connect the item with some of my experience and ask a question to try to get the person to talk about themselves. Once I can get a person to this point, it becomes easier to interact, because most people like to talk about things they are familiar with. When this happens, I can ease off on my constant assessment of the situation and nod in agreement, or say something to encourage the person to keep talking. While this may seem like common sense to many adults, it took me many years to build up these basics and to make effective use of them.

I continue to translate things people say into my personal language. The words I hear become connected to feelings, pictures and sounds associated with that conversation and other similar memories, so that I have a movie to play back for a particular conversation. However, when I play those movies in my mind, a part of me thinks everyone can see the same image, so I leave out certain aspects of that vision. This leads to people asking me questions when they try to figure out what I am talking about.

When I remember, the objects, people, animals and emotions are very clear, but I don't see writing and I don't always have a clear memory of the words that were said. This led to some interesting fights with my husband when I was younger, because I could remember a scene where I had been upset with him, but I could not remember exactly what he had said. He would always want to know exactly what he had said and we would both become frustrated, because I remember being upset and he wanted to know how to behave so he wouldn't make me angry in the future. When I remember things, it can be very frustrating to see the

books and papers in my memory and not be able to read the words, even though everything else in the memory is clear. It can be challenging to communicate and not become frustrated at the entire process.

My explanation is based on many years of experience and many mistakes when interacting with others. While I can't be sure of how John-John thinks or processes social situations, I suspect that he has built a similar set of scripts for his social interactions. His use of quotes and repetition of phrases that John and I use point to him following a limited set of rules, even when they aren't always appropriate.

Even writing this passage about my thought processes is at once interesting and frustrating, because I find myself wondering what I've left out. Fortunately, I have a good editor and beta readers to help decipher my thoughts and clarify them for the readers.

I have included references and resources for books I found helpful when my son was younger. It was very helpful to read how other families had reached out to their children and found a way to communicate. It also includes some additional resources that I have found since then.

Barron, Judy, Barron, Sean (1992): *There's a Boy in Here*. New York, New York. Simon & Schuster.

Grandin, Temple (1995): *Thinking in Pictures and Other Reports from My Life With Autism*. New York, New York. Doubleday.

Rimland, Bernard (1964). *Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behavior*. New York, New York. Prentice Hall.

Stehli, Annabelle (1990): *The Sound of a Miracle*. New York, New York. Doubleday.

Higashida, Naoki (August 27, 2013): *The Reason I Jump: The Inner Voice of a Thirteen-Year-Old Boy with Autism*. New York, New York. Random House.

Robison, John Elder. (September 9, 2008): *Look Me in the Eye: My Life with Asperger's*. New York, New York. Three Rivers Press.

Silberman, Steve. (August 25, 2015): *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*. New York, New York. Avery/Penguin Random House.

Suskind, Ron.(April 1, 2014): *Life, Animated: A Story of Sidekicks, Heroes and Autism*. Glendale, California. Kingswell.

An alternative therapy for communicating with non-verbal autistic children – <http://www.halo-soma.org/Baby Sign Language>. n.d. <http://www.babysignlanguage.com/>

Magro, Kerry. "These 21 Books Will Help You Learn More About Autism." *Kerry Magro*. N.d. <http://kerrymagro.com/these-21-books-will-help-you-learn-more-about-autism/>

## *Homeschooling Resources*

John and I both strongly felt that our son needed more attention from us, so we changed to a situation that supported our family. Homeschooling was the best option for us. For others, public or private school may be a better option. For parents who are interested in homeschooling, I have listed some resources I used in years past, as well as some more recent ones. Some public school districts offer homeschooling as an option. In these cases, the schools provide curricula and lessons for the parents to use. In some cases, the child can join in classroom activities and take advantage of some of the positive aspects of socialization that might be available.

Over the years, I have gone back and forth on our decision to homeschool and whether it was the right choice. I mostly feel that it was the right one, because he now seems comfortable with going out by himself, he continues to learn new things and he is interested in the world. I have heard from other parents of young autistic adults about how their son or daughter does not want to leave the house or try new things because of poor experiences, such as bullying or lack of adequate educational supports in traditional schooling. However, I also wonder if my son might have been a little more flexible if he had to deal with teachers and other children away from us. I know that my childhood was very difficult and I have no desire to repeat many parts of it, but I did learn skills because of the hardships I endured.

I think it is important to help the child and the family find a balance that supports everyone's needs in what is often a chaotic situation. I don't think there is one solution that will work for every family, simply because not every autistic child is exactly alike. This section offers alternatives for families that are dissatisfied with their own children's school situations.

Autism Web: A Parent's Guide to Autism Spectrum Disorder. [www.autismweb.com](http://www.autismweb.com).

"Being Free: Why We Choose to Homeschool Our Autistic Son." Respectfully Connected. April 4, 2015.

<http://respectfullyconnected.blogspot.com.au/2015/04/being-free-why-we-choose-to-homeschool.html>

National Association for Child Development (NACD).<sup>7</sup> <http://www.nacd.org/>.

Holt, John. (1964, revised 1982) *How Children Fail*. New York, Merloyd Lawrence, Delta/Seymour Lawrence.

Holt, John. (1967, revised 1983) *How Children Learn*. New York, Merloyd Lawrence, Delta/Seymour Lawrence.

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<sup>7</sup> This organization assesses the child and works with the parents on the recommended curriculum. The study plan is unique and designed specifically for each individual child.

Holt, John. (1989) Learning All the Time. New York, Merloyd Lawrence, Delta/Seymour Lawrence.

Homeschooling Autism. <http://homeschoolingautism.blogspot.com/>

Homeschooling Autism Resources. A2Z Home's Cool – Alphabet of Homeschooling.

[http://a2zhomeschooling.com/concerns\\_homeschooling/homeschooling\\_autistic\\_children/](http://a2zhomeschooling.com/concerns_homeschooling/homeschooling_autistic_children/)

## *Living with Autism*

Due to the issues of raising an autistic child, the stress can take a heavy toll on one or both of the parents. Depression can occur and parents may divorce because one partner feels unable to handle the stress. If siblings are involved, they may resent the autistic child due to the extra attention, or they may develop coping mechanisms to stay in the background and out of the way, due to the chaos created in the household. Based on our experiences, we feel it is important for caregivers to make time for themselves and not feel ashamed to ask for help. The analogy of “putting on the parent’s oxygen mask before the child’s” is a good one to remember. If you aren't getting the emotional oxygen you need, you won't be able to help your child as well as you can. The following are resources for coping with depression and tools for the mental well-being for the families of autistic children.

Brown, Bene. "The Power of Vulnerability." *Ted Talk*. June 2010. September 29, 2015.

[http://www.ted.com/talks/brene\\_brown\\_on\\_vulnerability](http://www.ted.com/talks/brene_brown_on_vulnerability).

Firreno, Jack. "What they don't talk about: One family's life with three children on the autism spectrum."

*The Wire*. August 6, 2014. September 29, 2015. <http://midweekwire.com/2014/08/06/what-they-dont-talk-about/>

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2015. <http://musingsofanaspie.com/2013/01/05/the-importance-of-the-pasta-on-the-left/>

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<http://respectfullyconnected.blogspot.com.au/2015/07/loving-you-to-outside-of-outer-space.html>

"Managing Behavioral Difficulties in ASD Children." *Durham Region Autism Services*. Viewed on September 29, 2015.

Margolis, Rachel. "Parental Well-Being Surrounding First Birth as a Determinant of Further Parity

Progression." *Springer Link*. August 4, 2015. September 29, 2015.

<http://link.springer.com/article/10.1007/s13524-015-0413-2>.

Menelly. "Blogspam and Information by Adult Autistics for Parents of Newly Diagnosed Kids." *Reddit.com*.

November 10, 2014. September 29, 2015.

[https://www.reddit.com/r/autism/comments/2lv6k7/blogspam\\_and\\_information\\_by\\_adult\\_autistics\\_for/](https://www.reddit.com/r/autism/comments/2lv6k7/blogspam_and_information_by_adult_autistics_for/).

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September 29, 2015. <http://www.theguardian.com/society/2013/jun/29/david-mitchell-my-sons-autism>

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## *Special Interests*

Many children on the autism spectrum have multiple special interests. To many normal people, these interests can seem obsessive and/or abnormal. However, if the child is prevented from pursuing these special interests, it can lead to a great deal of conflict. In my opinion, the child pursues a special interest because it is an area they understand and where they can exercise some measure of control. For a child on the spectrum, the world can be a confusing and frightening place. By having a special interest on which to focus, it can reduce their fears and anxieties. If parents and caregivers are willing to give support for the special interest, they may find a path to communicate with the child. I don't feel that this means the child can always have their own way, just that parents and caregivers should be willing to compromise and recognize when a child is trying to cope with the confusing world around them. The following references and resources provide examples of autistic children and how their special interests have helped them reach out to the world.

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## *T h e T e e n Y e a r s*

During the teen years, parenting an autistic child can have additional challenges. Even though the teenager may be behind in mental and social development, the body is still developing, which can be confusing. During adolescence, children transition to adulthood physically and mentally. Clear communication and support from parents are important, but it can be difficult to achieve full communication with autistic people, depending on where they have issues. There may also be delays in behavior for autistic teens, which means they may not have developed as many skills to deal with the changes as their peers have achieved. As these peers transition and find their own place in an adult world, normal teenagers may pick on autistic teens in order to show that they are part of the normal group and not an outsider.

In addition, there may be extra stress on autistic teens due to increased expectations for mature behavior. Activities that may have seemed cute or acceptable when they were younger are now frowned upon or actively discouraged. Autistic teens may choose to change their behaviors on their own in an effort to fit in more closely with normal teenagers. However, due to the energy it takes for someone on the spectrum to act normal, autistic teens may act out more at home and experience more frequent meltdowns as they try to cope with these increased requirements for adult behavior.

I can see now that I held higher expectations for John-John's behavior as he grew older, even though I knew intellectually that he was behind in his social skills. I fell into the same trap that I was afraid other people would struggle with when meeting my son—that because he is 6'2" and physically close to adulthood, that he is also socially and mentally ready for this change. In reality, his adult body was something new that he had to learn to deal with while he was still thinking and reacting more like a ten to twelve year old. As more was expected of him, he would try to comply, but since it wasn't natural, it took more out of him and so he needed to act out more. This seemed like rebellion and defiance, but I now realize it was his coping mechanism for stress from all of the changes.

Based on what I have learned, I believe I would have lowered some of my expectations and worked to show more support for John-John as he grew and changed. For me, this would have involved a better understanding that he was feeling stressed and that I needed to be more nurturing instead of yelling or arguing about how he needed to change and act normally. I should also have worked to be more accepting of his "stims," understanding that these behaviors helped him to bleed off his stress and anxiety, which allowed him to cope with the changes brought about by adolescence. In short, I should have worked to reduce his

stress so he would have more energy to listen and learn about behaviors that were truly important, instead of worrying about trivial acts that I can't even fully recall some 10 years later.

Adolescence is a time when young women who are on the spectrum may finally be diagnosed. For young girls who are verbal, they can often imitate the behavior of their peers and blend in, but when adolescence begins, they find it more difficult to imitate these behaviors. Due to these differences, they may be shunned by their peers and have difficulty connecting with others. As of 2016, it is slowly being recognized that there are more young women on the spectrum, but finding and helping them is a slow and daunting task. If they are not diagnosed, the bullying and shunning can lead to depression, anxiety and other mental health issues that will cause problems for them as adults. All autistic teens need a safe place where they can be themselves and take a break from the transition period between childhood and adulthood.

The following set of resources provides some information about the experience of adolescence for autistic teens. The focus is on positive articles to help parents and their children.

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Wendler, Daniel. "Online Social Skills Guide – Improve Your Social Skills." *Improve Your Social Skills*. N.p., 2016. Web. 26 Apr. 2016.

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## *Transition to Adulthood*

When normal children maneuver through their teen years, they prepare for an independent life at eighteen, leaving home to work, go to college, join the military or in some other way explore what it's like to take responsibility for their lives. The problems with social issues and possible lack of maturity can delay this stage for autistic people. There are currently fewer resources for young adults on the autism spectrum, which limits their choices for pursuing independent living. When looking back at John-John's teen years right before eighteen, I'm not sure what we could have done differently. Because of our approach, everyone in our family was burned out and ready for a break. Perhaps we could have worked on more life skills, the type of things that any adult needs to know in order to take care of themselves. However, I have always believed in working on life skills with children, such as cooking, cleaning, handling money and other tasks that are part of adulthood, so John-John had already been learning those traits. In my research over the past year or so, I have discovered more options for young adults with autism, but more still needs to be accomplished in this area. The focus has always been on helping autistic children with the idea that their condition can be "cured" and the child can grow and live a normal life as an adult. We have found, as many others have, that there is no cure, and no clean or simple solutions for a young adult with autism who wants independence. There is not just one solution, but many different methods of dealing with young adults who are on the spectrum and who want to move into the adult world. I have included some resources about autistic teens and adults in order to provide some examples of what these children can accomplish as they grow up.

Carly's Voice. "Carly's Voice | Order Yours Today!". N.p., 2015. Web. 3 Nov. 2015.

Grandin, Temple. *Temple Grandin On Working With Autism: I Like The Way I Think*. 2015. Web. 3 Nov. 2015.

Kim, Cynthia. "Musings of an Aspie". N.p. 2014. Web. <https://musingsofanaspie.com>.

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*A d u l t h o o d   a n d   A u t i s m*

The following are some references for adults on the spectrum, including those who were diagnosed as an adult. While autistic people can appear “normal,” it does not mean that they find it easy or comfortable to function in the real world. Support groups can also help with counseling for co-morbid conditions such as depression, anxiety and other issues that can increase the coping mechanisms an adult can use.

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## *A u t h o r   B i o s*

John M. Harpster

*John M. Harpster was born in Ft. Worth, Texas and raised in Arlington. After several years of odd jobs, he went back to college and got his bachelor's degree in Computer Science from California State University in Northridge, CA. His first job after college was in Fort Worth, Texas at General Dynamics. He met and started dating Tamara Stensland, also a software engineer at General Dynamics, and they were married in Dallas, Texas. Before the birth of their son he wrote articles for a computer magazine but put that aside when he became the father of an autistic boy. He and his family live in Lakeside, California with their son John.*

*John returned to writing with his debut book of the Dancing with the Universe Series, "Doing the E.T. Tango". He is working on additional books for the Dancing with the Universe series and other ideas. He is currently writing on other books, including another satire called "Elijah". He is also building a wooden robot that he can put in the front seat of his car to enable him to drive in the HOV lanes on the freeway.*

Tamara Harpster

*Tamara Harpster was born December 5, 1962, which is also Walt Disney's birthday and the day Mozart died, two facts she has been trying to reconcile ever since she found them out. Her childhood was spent in various cities in the Midwest as her family moved around for her father's job. After graduating from Oklahoma State University she got her first job and met her husband to be on her first project. They married a year later and are still together some 30 years later. In that time she has been a software engineer, motel owner/manager, web developer, project manager and is currently part owner of another small business. In her spare time she works with her husband John to polish up his novels, and do her own writing for blog entries and essays. She is working on a fantasy series "Hero Lottery" and a science fiction novel "Year 2038 Bug". The book "Year 2038 Bug" will be published as a serial on their website.*

Thank you for reading this excerpt of Resources, References and Reflections from *“You Don’t Want to Go For a Ride”*. We would appreciate it if you would leave a review for the book on the site where you bought it. Your feedback is important for us and for other readers.

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