

# A HAGGADAH FOR UNDERSTANDING AUTISM

A MODEST ATTEMPT TO RAISE AWARENESS

AIDAN PURSLEY – RELJ 3085

# DEDICATION

- I would like to dedicate this Haggadah to my incredible mentee. She has made such a lasting impact on my life that I could have never imagined. In honor of her, each time we raise a glass, I will be raising her favorite drink, a cold Dr. Pepper without ice.



# DISCLAIMER



- All of the artwork featured is courtesy of individuals with Autism who use art as a medium to communicate their thoughts and feelings.

## “Autism Talking” – Wen of Zen

# INTRODUCTION

- My service this semester, Autism Allies, aims to foster meaningful relations between UVA students and individuals in Charlottesville on the Autism Spectrum.
- Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges.

# INSPIRATION

”If you’ve met one person with autism, you’ve met one person with autism.”

- Dr. Stephen Shore



Autism is an extremely complex disorder and does not look the same for every individual on the spectrum. Not every person with ASD will experience the same symptoms or express themselves the same way. There is no exact method for working with people on the spectrum but through this Haggadah I hope to give some worthwhile advice that will help us all to be a little more cognizant of our actions and impact when working with people with Autism.

“Shattered Self Portrait” – Kimberly Gerry-Tucker

## A FEW THINGS TO KEEP IN MIND:

- When working with people on the Autism Spectrum it is important to:
  - Use a calm tone.
  - Refrain from physical touch.
  - Keep language simple and to the point.
  - Avoid the use of sarcasm and idioms because these phrases can be taken literally.
  - Keep things structured, have a timeline and stick to it. Unnecessary wait time can be a source of anxiety and confusion.



# THE FIRST CUP

- Let us raise our first glass to say thank you to all of the parents that go above and beyond for their children with Autism. To the parents that help their children with school. To the parents that deal with the unexpected outbursts with compassion and kindness. To the parents that help their children find job placements. To the parents that understand the importance of helping their child get involved with activities that bring them joy. To the parents who maintain a routine and structured schedule for their child. To all of the parents who act out of unconditional love for their child. To all of the parents that are never properly thanked for all that they do in supporting their child with Autism.



“Safe with Mother” – Carl Parker

## THE SECOND CUP



“The Truly Great Team I Have” – Jeremy Sicile-Klra

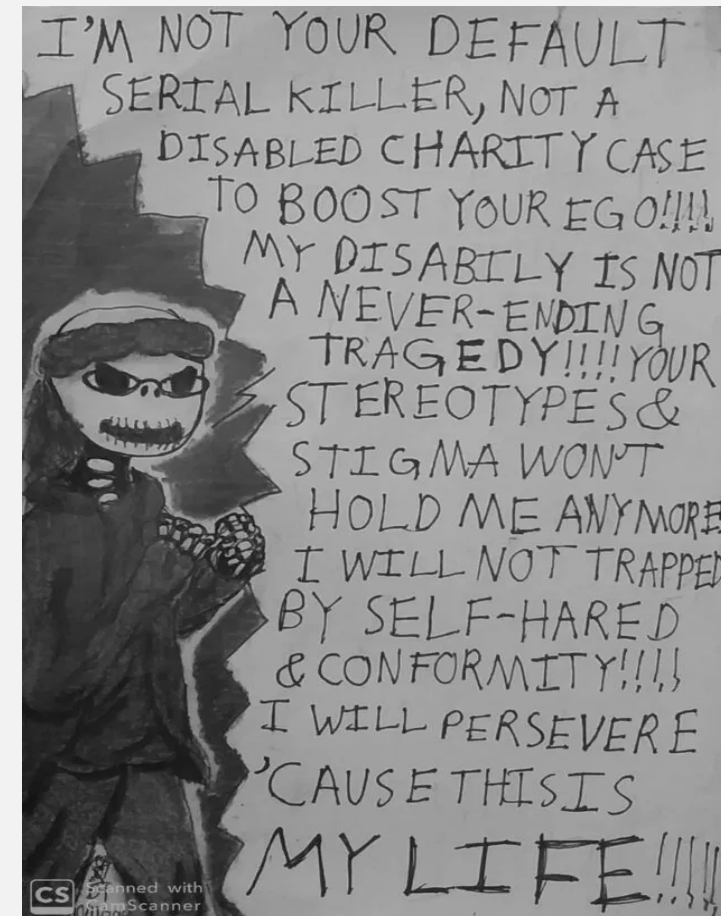
- Let us raise our second glass with thanks to all of the people that go into career fields focused on supporting individuals with Autism. To the Healthcare Providers. To the Autism Spectrum Disorder Specialists. To the Speech Language Pathologists. To the Behavior Therapists. To the Occupational Therapists. To the Rehabilitation Therapists. To the Special Education Teachers. To the Social Workers. To the Developmental Psychologists. All of these people devote their lives to serving people with ASD and deserve a little extra recognition for their efforts.



# THE FOUR STEREOTYPES

I would like to preface this section by saying, these stereotypes are pervasive and offensive and should never be used to group together individuals with Autism.

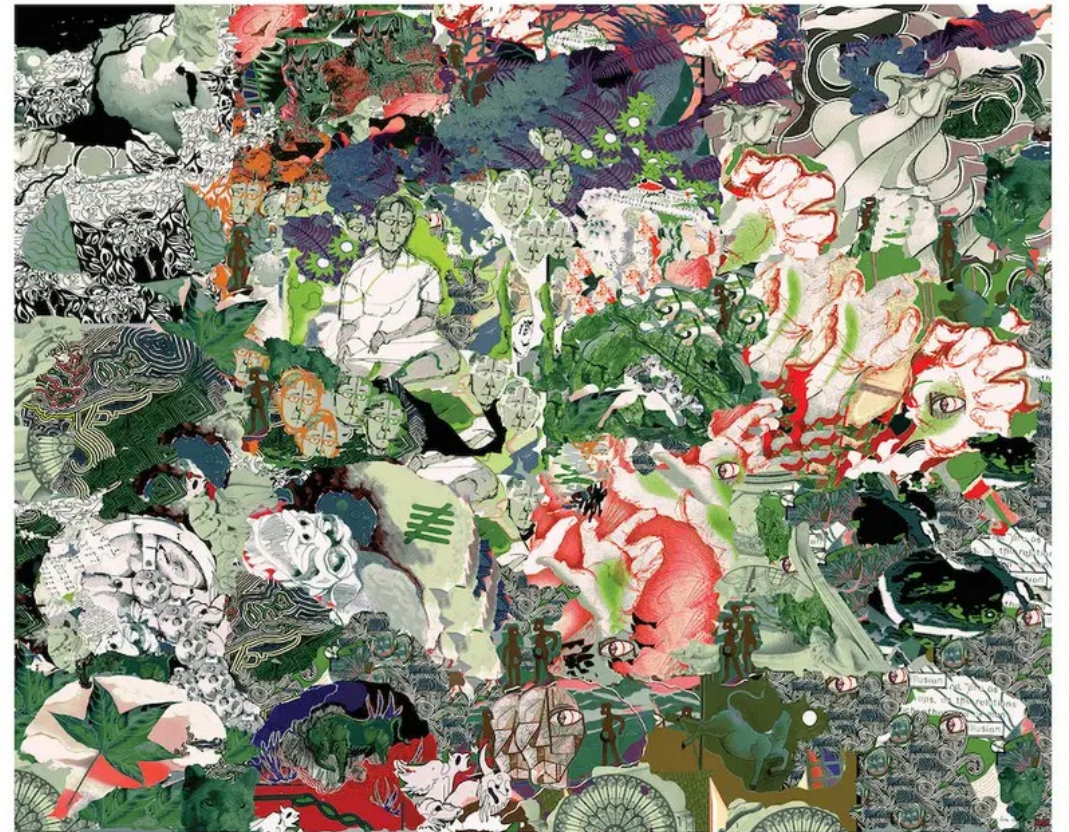
- Stereotype I: The 'High Functioning' One
- Stereotype II: The 'Genius' One
- Stereotype III: The 'Nonverbal' One
- Stereotype IV: The 'Rude' One



Dana Trick

## THE ‘HIGH FUNCTIONING’ ONE

- People with Autism are frequently referred to as ‘high functioning’ if they work a full-time job or have a drivers license or are able to live independently. People tend to throw around this label of ‘high functioning’ around far too often. Categorizing someone as ‘high functioning’ implies that there are also ‘low functioning’ individuals. Not only is this a hurtful and exclusionary stereotype it is also incredibly subjective. The capabilities of one person with Autism are not an indication of the capabilities or limitations of another person with Autism.



“A Portrait of the Artist” – Emily L. Williams

## THE ‘GENIUS’ ONE



“The Knowing” – Carl Parker

- Another common stereotype is that people with Autism are ‘geniuses.’ This stereotype is often portrayed in movies and television shows. Characters such as Raymond Babbitt in the movie Rain Man have built up this ‘genius’ stereotype. But it is important to understand that this character had both Autism and Savant Syndrome and that this is not common for all people with Autism. In fact, according to the the Autism Research Institute, only 10% of individuals with Autism also have savant skills making this stereotype incredibly inaccurate and, again, hurtful.



## THE ‘NONVERBAL’ ONE

- This is another hurtful stereotype that makes people with Autism seem like they are less ‘normal’ than neurotypical people. Simply because an individual with Autism has delayed speech or no speech at all does not mean that their mind does not flourish with thoughts and ideas. It just means they have a more difficult time communicating their thoughts verbally. And that should not be the defining characteristic of their being.



“Lost in Thought” – Kay Atich

## THE 'ANGRY' ONE



“Angst” – Nihilivonne

- Because outbursts tend to be a general characteristic of individuals with Autism others are quick to label people with ASD as ‘angry.’ Another hurtful and inaccurate stereotype. Autism meltdowns are in no way comparable to typical temper tantrums. Most of these outbursts and meltdowns are an intense response to situations that tend to be overwhelming to people with Autism. Rather than judge this response, we need to work to make sure the individual having the meltdown is okay. It is imperative to give them time and space after a meltdown while assuring them that you are there for them.



## A QUICK DEBRIEF

- As outsiders, it is difficult to understand what it is like to have autism so it is important to stay away from stereotyping. These misconceptions can be very isolating and overlook the many unique qualities and strengths that individuals with Autism have. Just as no two neurotypical individuals are the same, no two people with Autism are the same. Often people with Autism share a number of general characteristics yet they remain vastly different from each other and it is not fair to strip them of their individuality by labeling their actions with stereotypes.

## THE FOUR STEREOTYPES: CORRECTED

- While grouping individuals with ASD by stereotypes is offensive, we can recognize the unique struggles that they face on a daily basis, like we do with all other human beings. It is important to recognize these struggles in order to better understand why someone with ASD reacts the way they do in a particular situation. Four common struggles are communicating, coping with change, hypersensitivity to sounds, processing sensory information.



“Path of Life” – Moontain

# STRUGGLES IN COMMUNICATION



"Whispering Winds" – J.A. Tan

- It can be difficult for people with ASD to communicate their thoughts and feelings verbally. So it is important to look for 'nontraditional' modes of communication. For example, the artist of this painting is nonverbal and speaks in colors rather than in words. The artist carefully selects the colors of each painting to convey his message based on what feelings and emotions the color evokes for him.



## DIFFICULTY COPING WITH UNEXPECTED CHANGES

- People with Autism often find change very difficult to deal with and being able to prepare the individual for the change is one of the best ways you can offer support. When unexpected changes do occur it is important to describe the change and encourage the individual to look forward to some aspect of the change. No matter the change, anxiety is likely to accompany it so it is necessary to let the person know you are there to support them for the duration of the change.



"It Oscillates and Moves, Unpredictable"– Mahila Amatina

## HYPERSENSITIVITY TO SOUNDS



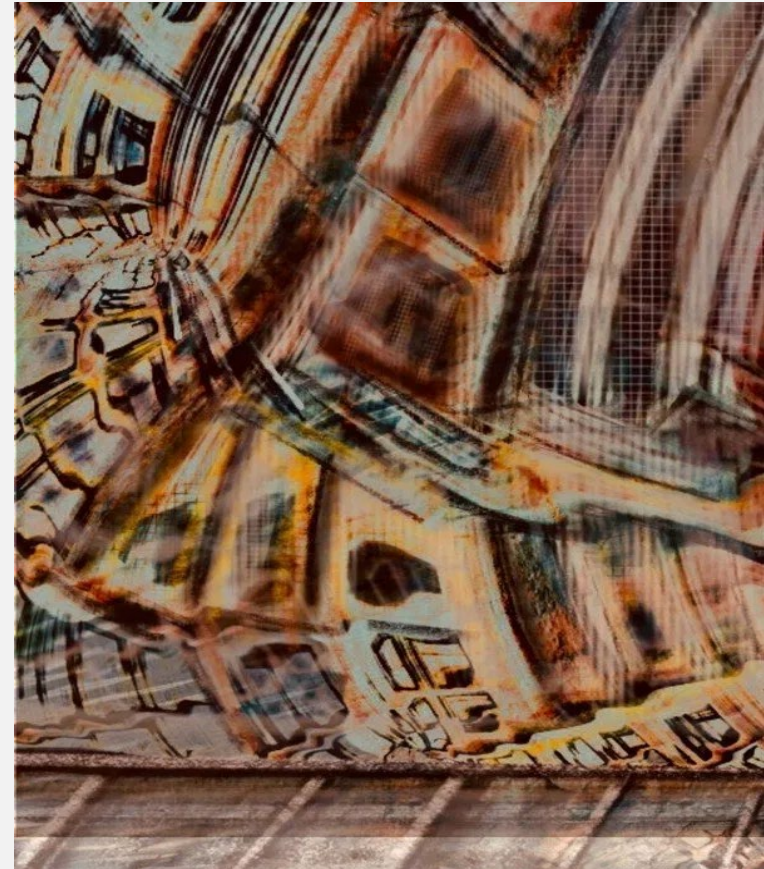
“Seeing Sounds” – Wen of Zen

- Another common struggle that accompanies Autism is the ability to process everyday sounds. Loud noises are often painful and cause an extreme feeling of discomfort for someone with ASD. It is essential to be aware of this struggle and try to avoid crowded areas with loud noises. Oftentimes a person with Autism will cover their ears when sounds become too overwhelming. If you notice this try to get the individual to a sensory friendly space. For example, during tricking or treating on the lawn the Autism Allies organization sets up a sensory friendly lawn room with dim lights, soft music, and an overall calming environment to provide comfort.



# SENSORY ISSUES

- Many people with ASD have difficulty processing sensory information and can have intense responses when they are overwhelmed by sensory stimuli. These responses can be both over-responsive and under-responsive. Hypersensitivity to light and hyposensitivity to pain are two of the most common sensory reactions for people with Autism. Being aware of these struggles and knowing how to accommodate when there is a sensory overload can help ease some of the related anxiety and discomfort.



"Sensory Overload Red" – Wen of Zen

# THE FOUR QUESTIONS

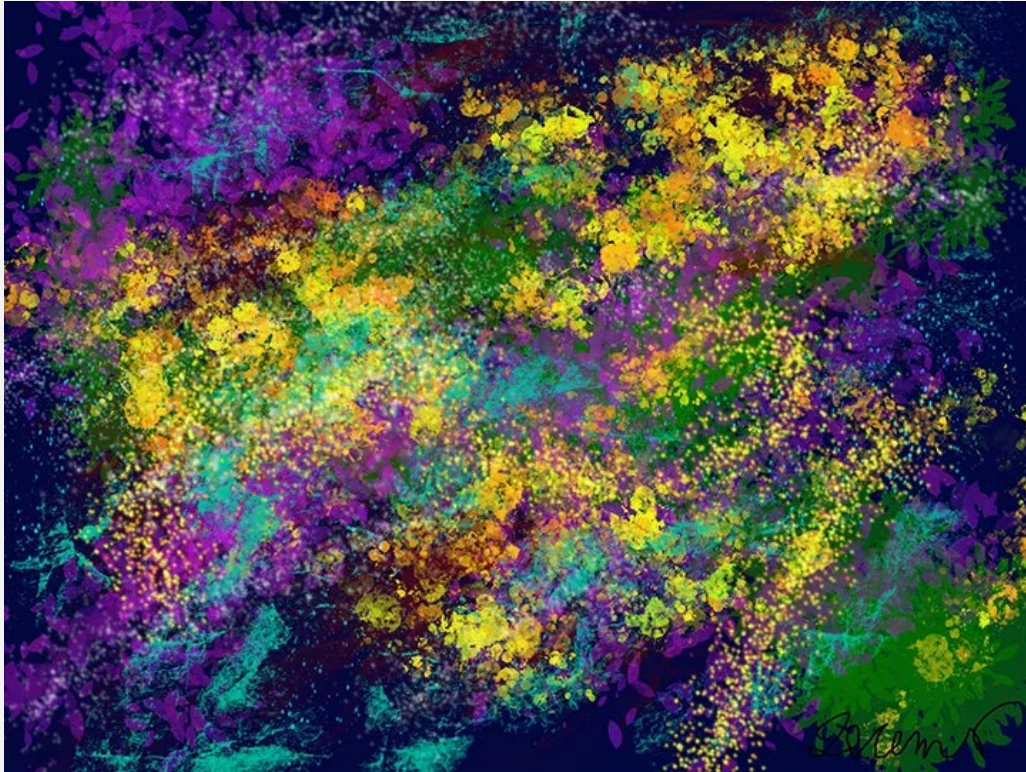
- What causes Autism Spectrum Disorder?
  - We still don't know for sure. Based on the current research, genetic factors and environmental factors seem to be significant causes for ASD.
- How common is Autism Spectrum Disorder?
  - In 2020, the CDC reported that approximately 1 in 54 children in the United States is diagnosed with ASD.
- Who is affected by Autism Spectrum Disorder?
  - Boys are 4 times more likely to be diagnosed with ASD. According to 2016 data 1 in 34 boys were identified with autism and 1 in 144 girls were identified with Autism.
- Is there a 'cure' for Autism Spectrum Disorder?
  - There is no cure or treatment for ASD but a combination of medicines and behavioral therapies can be used to help with some of the related symptoms.

## STRUGGLES OF BEING A MENTOR

. Being a mentor isn't always easy but it is always worth it. Here are 10 instances that I have noticed myself struggle with from time to time.

- Remaining calm during a meltdown.
- Keeping up with a regular volunteer schedule amidst a busy personal schedule.
- Saying no when it needs to be said.
- Being fully present in the moment.
- Navigating unexpected changes.
- Dealing with unexpected changed in mood.
- Giving space when all you want to do is help.
- Moments of silence.
- Having to deliver disappointing news.
- Accepting that you may not be able to see the magnitude of your impact.

## THE THIRD CUP



- Let us now raise a third cup to thank the researchers who work to educate the community about ASD. The researchers who work to clarify any preconceived notions or misconceptions about individuals with Autism. The researchers who study various treatment and support methods. And most importantly, the researchers who work to better understand the biology of Autism and how it impacts the lives of people with the disorder instead of just providing rigid classifications of the disorder.

“The Wonderful Colors of a Healed Planet” – Jeremy Sicile-Kira



## THE FOURTH CUP

- Let us now raise our fourth and final cup with gratitude for organizations such as Autism Allies that make it their mission to educate and train individuals in how to work with people with Autism. Organizations like this that work to create a kinder, more thoughtful community. Organizations like this that understand the importance of serving others. Organizations like this that look to foster meaningful relationships between mentors and mentees. Organizations like this that work to create sensory friendly environments for individuals with Autism. Organizations like this that put on community-wide events that people with Autism feel welcomed and comfortable at. Organizations like these that want to make the world a little brighter place to be.

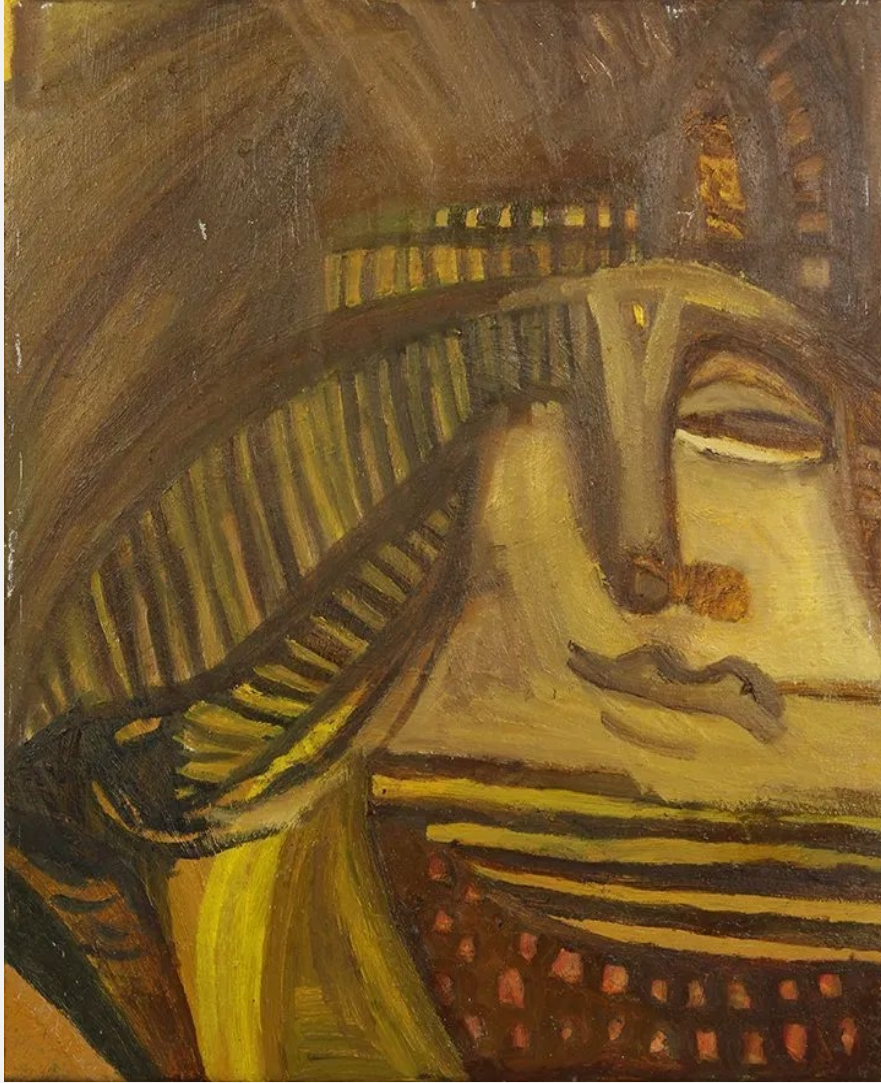


“Working Together” – Wendy Middlemass



## DAYENU

- Before we close, I would like to take a moment for reflection and gratitude on my semester of service to acknowledge all that I have gained from this experience.



“Ray of Enlightenment” – Taso  
Lin Louise Tan

If I had only joined Autism Allies  
And not become a mentor  
I would have been grateful for the experience.  
It would have been enough.

If only we would have spent an hour together a week  
I would have been grateful for the experience.  
It would have been enough.

If only I could have worked with my mentee  
And not created a lasting relationship  
I would have been grateful for the experience.  
It would have been enough.

If we only went on walks  
And didn't talk about life  
I would have been grateful for the experience.  
It would have been enough.

If only I had asked my mentee about her day  
And she had not asked about mine  
I would have been grateful for the experience.  
It would have been enough.



If I had only been a volunteer  
And not realized I wanted to continue working with people  
with Autism in the future  
I would have been grateful for the experience.  
It would have been enough.

If I had only been able to spend time with my mentee for the  
first half of the semester  
And not been able to FaceTime with her  
I would have been grateful for the experience.  
It would have been enough.

If I had only spent the organization's required 6 hours with my  
mentee  
And not the additional time  
I would have been grateful for the experience.  
It would have been enough.

If only I had made an impact in my mentee's life  
And she had not made such a life changing impact on my life  
I would have been grateful for the experience.  
It would have been enough.



Peace and Diversity: We Are All In it Together  
– Kimberly Gerry-Tucker



# NEXT YEAR IN A MORE UNDERSTANDING WORLD



“Chaos to Calm”  
– Amanda LaMunyon

## WORKS CITED

- “11 Myths About Autism.” *Autism Speaks*, [www.autismspeaks.org/blog/11-myths-about-autism](http://www.autismspeaks.org/blog/11-myths-about-autism).
- “A Day in the Life: Raising a Child with Autism.” *Parents*, [www.parents.com/health/autism/parenting/day-to-day-raising-autistic-child/](http://www.parents.com/health/autism/parenting/day-to-day-raising-autistic-child/).
- Admin. “The Art of Autism.” *The Art of Autism*, 12 Apr. 2020, [the-art-of-autism.com/](http://the-art-of-autism.com/).
- “Autism Speaks Names Top Ten Autism Studies of 2018.” *Autism Speaks*, [www.autismspeaks.org/news/autism-speaks-names-top-ten-autism-studies-2018](http://www.autismspeaks.org/news/autism-speaks-names-top-ten-autism-studies-2018).
- “Autism Statistics and Facts.” *Autism Speaks*, [www.autismspeaks.org/autism-statistics](http://www.autismspeaks.org/autism-statistics).
- “Blog Post.” *Organization for Autism Research*, 14 Apr. 2020, [researchautism.org/what-to-say-what-not-to-say-to-someone-with-autism/](http://researchautism.org/what-to-say-what-not-to-say-to-someone-with-autism/).
- “Drawing Autism: Inside the Minds of Artists on the Spectrum.” *Autism Speaks*, [www.autismspeaks.org/news/drawing-autism-inside-minds-artists-spectrum](http://www.autismspeaks.org/news/drawing-autism-inside-minds-artists-spectrum).
- “News & Events.” *Organization for Autism Research*, 14 Apr. 2020, [researchautism.org/an-autistic-woman-addresses-9-common-misconceptions-about-autism/](http://researchautism.org/an-autistic-woman-addresses-9-common-misconceptions-about-autism/).
- “News & Events.” *Organization for Autism Research*, 14 Apr. 2020, [researchautism.org/i-have-nonverbal-autism-heres-what-i-want-you-to-know/](http://researchautism.org/i-have-nonverbal-autism-heres-what-i-want-you-to-know/).
- “Questions and Answers about Autism Spectrum Disorders (ASD).” *World Health Organization*, World Health Organization, [www.who.int/news-room/q-a-detail/questions-and-answers-about-autism-spectrum-disorders-\(asd\)](http://www.who.int/news-room/q-a-detail/questions-and-answers-about-autism-spectrum-disorders-(asd)).
- “Sensory Issues.” *Autism Speaks*, [www.autismspeaks.org/sensory-issues](http://www.autismspeaks.org/sensory-issues).
- “The National Autistic Society - Meltdowns.” *Autism Support - Leading UK Charity - National Autistic Society*, [www.autism.org.uk/about/behaviour/meltdowns.aspx](http://www.autism.org.uk/about/behaviour/meltdowns.aspx).
- “Understanding Aggression in Autism: Spectrum:Autism Research News.” *Spectrum*, 22 Oct. 2015, [www.spectrumnews.org/opinion/guest-blog-understanding-aggression-in-autism/](http://www.spectrumnews.org/opinion/guest-blog-understanding-aggression-in-autism/).
- White, Alan. “13 Extraordinary Pictures By Artists With Autism.” *BuzzFeed*, BuzzFeed, 17 Jan. 1970, [www.buzzfeed.com/alanwhite/13-extraordinary-pictures-by-autistic-artists](http://www.buzzfeed.com/alanwhite/13-extraordinary-pictures-by-autistic-artists).