

“DIFFERENT, NOT LESS.”

LEAH M.

THE OXBOW SCHOOL



My installation is a simulation allowing people who are “neurotypical” (not displaying or characterized by autistic or other neurologically atypical patterns of thought or behavior) to understand a common characteristic of autism, which is sensory overload. Sensory overload occurs when the body receives overstimulation from the environment. It is overwhelming, uncomfortable, and anxiety-inducing.

I researched autism because my cousin, James, is autistic, and because my dog, Dusty, was a therapy dog that worked with autistic children. For my artwork, I decided to focus on a specific aspect some may experience with autism. When conducting research, I came into contact with an autistic community on Facebook. Many of these people have had sensory overload, and many agree that it is frustrating to have a lack of empathy surrounding this symptom. These feelings of overstimulation and lack of understanding by others sparked me to create this installation.

This room is layered with overstimulating patterns and colors on the walls, a strobe light, and overwhelming noises. Though sensory overload may manifest itself in various ways and may not be identical to this, this is a way for people without autism to understand what some people go through. In allowing neurotypicals to experience this aspect of autism, I strive to build an understanding and, by doing this, bridge a gap in society between these two communities—a society that is inclusive to all, with a focus on neurodiversity.

This simulation, is an attempt to generate empathy, leading to inclusivity.

Leah M.
Irvington, New York

Autism is one of the world's most baffling and misunderstood disorders. I have been exposed to autism my whole life. My cousin, James, was diagnosed with autism directly after I was born, and my dog, Dusty, used to be a therapy dog at a school for children with autism. From a young age I was able to observe various areas of the autism spectrum. In my first stages of research, I was looking into service and therapy animals and their relationships with their owners. However, as I continued to do research, I realized that I was more inclined to study autism because of my cousin. In this paper, I will discuss what autism spectrum disorder is, the symptoms and characteristics of those afflicted with autism, and how we can partner with those with autism take on more inclusive roles in society.

I would like to dedicate this paper to Dusty. The amount of lives she has touched is insurmountable; especially mine. I would also like to dedicate this paper to James, who served as a catalyst for my research.

Autism Spectrum Disorder, or "ASD," is the general term for a neurodevelopmental disorder present from early in life. It is characterized by challenges with social skills, repetitive behaviors, speech and verbal communication, responses to environmental stimuli, as well as unique strengths. All of these fall on the spectrum, which refers to the wide variations possessed by each person with autism.

Social skills and communication differences are key signs of autism. Difficulty in understanding, talking, reading, or writing are all common, more specifically: understanding and using gestures such as pointing or waving, following directions, understanding and using words, having conversations, or learning to read or write. Other common signs are echolalia (when a person repeats words they have just learned or heard for an extended period of time), speaking in either a robotic or a singsong voice, speaking in "chunks," (meaning bits of dialogue composed of TV commercials, movies, or others' speech), and having tantrums instead of communicating how he/she feels. It may be hard for people with ASD to sustain joint attention (focusing with someone on the same object or event), playing with others and sharing toys, understanding others' emotions, and making or keeping friends. People with ASD tend to seem as if they are in their own world, and they may have problems relating to other people.

Behavioral differences are also common. People with ASD may have trouble changing from one activity to the next, use repetitive gestures such as flapping their hands, rocking back and forth, spinning, or staring. They may develop a sensitivity to sounds, light, or taste. They may hyper focus on specific interests, and talking extensively about only one topic. For example, my cousin James knows everything about movies. You can ask him for a list of movies that came out in 1953 and he will know every single one, who was in it, and if it won any awards. This remarkable talent is a product of his autism. Another symptom he shows is staring. When he was a boy, he would sit outside and stare at trees. The relaxation and utter fascination this provided him was his solace.

There are three different types of Autism Spectrum Disorders, sometimes called "Pervasive Developmental Disorders" (PDD). These consist of: PDD-NOS (Pervasive Developmental Delay-not otherwise specified, also known as Atypical Autism), Autistic Disorder (referred to as Classic Autism, Early Infantile Autism, or Childhood Autism,.) and Asperger Syndrome. Those with PDD-NOS usually have fewer and milder symptoms than those with autistic disorder. The symptoms might only cause social and communication challenges. People who meet some of the criteria for autistic disorder or Asperger Syndrome, but not all, may be diagnosed with PDD-NOS. Autistic Disorder is what most people think when they hear "autism." People with autism may have significant language delays, social and communication

challenges, unusual behaviors and interests, and sometimes intellectual disability. Asperger Syndrome usually have some of the milder symptoms of autistic disorder. They may experience social challenges and unusual behaviors and interests, however they typically do not have problems with language or intellectual disability. Autism is also associated with various comorbidities, including sensory and motor abnormalities, sleep disturbance, epilepsy, gastrointestinal (GI) distress, attention deficit hyperactivity disorder (ADHD), intellectual disability, and mood disorders such as anxiety, aggression, and obsessive compulsive disorder (OCD).

¹Autism is a lifelong problem. There is no single cause. Research suggests that autism develops from a combination of genetic, non genetic, or environmental influences. It is four times more likely to occur in boys than girls, it effects no specific race, ethnic, or social groups. It is also widely accepted that ASD is a disorder with strong genetic components, however autism is an etiologically² diverse disorder. No single genetic mutation accounts for more than 1-2% of ASD cases. How those mutations lead to ASD phenotypes is poorly understood. Many ASD related genes are also associated with other neuropsychiatric disorders. Sometimes, genetic changes occur spontaneously in an early embryo, or the sperm/egg that create the embryo. More research is needed to further understand the linkage between genes and ASD. Most gene changes do not cause autism by themselves, they simply increase the risk for the disorder. A key direction for neuropsychiatric research is to study the neural mechanisms underlying the divers symptoms caused by single genetic defects. The autism genetic landscape has been said to be 80-85% unknown or multifactorial type, 5-10% de novo single gene mutations (a genetic alteration that is present for the first time in a single family member as a result of a mutation in a germ cell of one of the parents, or a variant that arises in the fertilized egg itself during early embryogenesis), 5% chromosome anomalies and CNVs (the duplication or deletion of stretches of a chromosomal region, however the deletion is more associated with autism, and the duplication is more associated with schizophrenia), and 3% mendelian single gene, inherited (a mutation in a single gene following Mendel's laws on inheritance). Lori Driscoll, professor of psychology at Colorado College, states that some cases of autism are genetic in origin. Many genes can contribute to a predisposition to showing the symptoms associated with autism spectrum disorder. However, some cases may also be triggered by immune events, most often viruses such as rubella. Prenatal viruses are definitely a contributor, as well as gut microbes. If you are predisposed to gut dysbiosis³, this can tip you into autistic symptoms.

Environmental factors that can potentially increase the risk of autism are advanced parent age, pregnancy and birth complications (for example, extreme prematurity [before 26 weeks], low birth weight, multiple pregnancies [twin, triplet, etc.]), and/or pregnancies spaced less than one year apart. If one monozygotic (identical) twin has autism, then there is an 90% chance that the other twin will be diagnosed with ASD. For dizygotic (non-identical) twins, the chance that both twins will develop ASD is 3-10%. The chance that siblings from separate pregnancies will be affected is also about 3-10%. Both genetic and non-genetic factors play a significant role that

¹Won, Hyejung, et al. *Frontiers in Molecular Neuroscience*, Frontiers Media S.A., 2013, www.ncbi.nlm.nih.gov/pmc/articles/PMC3733014/&sa=D&ust=1523823466200000&usg=AFQjCNGL0hZMzn_9sUis7ZSt1TGMBMbmV.

² Refers to causation or origination.

³ Refers to a lack of beneficial bacteria in your gastrointestinal (GI) tract.

may contribute powerfully to ASD. ⁴It is important to note that vaccines have zero effect on autism. Autism is most commonly noticed at the time children receive their vaccines, which leads to this misconception. However, there is zero link between autism and vaccinations. It is important to note the current political climate surrounding vaccinations. Many “anti-vaxxers” believe that vaccinations contain lethal amounts of mercury, aluminum, and formaldehyde. Though vaccines do contain these chemicals, there is such a limited amount that it cannot have a bad effect on people. For example, apple seeds contain cyanide, but not enough to harm anyone. The doses of chemicals in vaccines are negligible. Children are given shots at such a young age because this is when they are most at risk of getting sick. Vaccines have done an incredible job preventing so many diseases, that many generations have never seen them. In 1967, smallpox was responsible for millions of deaths. By 1980, it was completely eradicated due to an intensive vaccine campaign. The World Health Organization estimates that regular vaccinations have prevented 20.4 million deaths from measles worldwide from 2010-2016. Much of the anti-vaccination movement is linked to ⁵one paper published in the 1990’s, claiming vaccines cause autism. It suggested a link between the measles, mumps, and rubella vaccine causing malabsorption of nutrients in the gut, thereby leading to increased cases of autism in children. The study was later proven to be fraudulent, and was debunked by 25 international research papers involving large population studies. Furthermore, the majority of the authors of this original paper have now retracted their original statements. Vaccines protect yourself and other people.

Diagnosing ASD can be difficult because there is no medical test (such as a blood test) to diagnose the disorders. Doctors look at the child’s behavior and development to make a diagnosis. ASD can be detected as early as 18 months or younger, and it is most commonly diagnosed within the first 3 years of life. Specially trained physicians and psychologists administer autism-specific behavioral evaluations. A typical diagnostic evaluation involves a multidisciplinary team, including a pediatrician, psychologist, speech and language pathologist, and an occupational therapist. Genetic testing may also be recommended, as well as screening for other related medical issues such as gastrointestinal difficulties. This comprehensive testing allows for parents and doctors to understand the child’s specific strengths and needs.

Diagnosing ASD takes to two steps: developmental screening, and a comprehensive diagnostic evaluation. Developmental screening is a short test to identify whether a child is retaining basic skills when they should, or if there are delays. The comprehensive diagnostic evaluation may include looking at the child’s behavior and development, and interviewing the parents. It is also common to include a hearing and vision screening, genetic testing, neurological testing, and other medical testing.

It is important to note that autism is a neurotype, meaning a particular wiring of the brain. People with autism are not at a disadvantage because they have autism, they simply have another way of processing information. To use an analogy, “neurotypical” people are Apple, and people on the spectrum are Windows. They both are operating systems, they simply operate differently. This does not make one better or worse, they just function differently. With that said, the only disadvantage people on the spectrum have are societal drawbacks.

⁴ Helen V. Ratajczak (2011) Theoretical aspects of autism: Causes—A review, *Journal of Immunotoxicology*, 8:1, 68-79, DOI: 10.3109/1547691X.2010.545086

⁵ Ileal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children.

Autism is by no means a rare condition. The National Health Interview Survey found that 1 in 45 children, aged 3 through 17, have been diagnosed with ASD, which is notably higher than the official government estimate of 1 in 68 American children with autism, by the Centers of Disease Control and Prevention (CDC). However, the diversity of the spectrum and the fact that it is a largely invisible condition can mean that it is easy to overlook the difficulties experienced by autistic people.

The ADA (Americans with Disabilities Act) classifies autism as a developmental disability. A more appropriate perspective is to consider autism under the framework as a social disability, with “disability” meaning that one is disabled because the majority of society is not made for them. When looking at autism from this lens, it is clear that society functions for the benefit of the majority. An example would be with schools. Students with autism present unique challenges to schools, and it can be difficult to meet their needs effectively. Every person on the spectrum is different, so their needs will be reflected differently. In a broad sense, we need to foster a more accessible, inclusive, and flexible educational setting. Instead of pushing everyone into the same mold, there should be room to allow ones with specific talents to grow into the form they are capable of. Students on the spectrum often need time away from other students and the demand of the mainstream classroom. Allowing students this time will not only manage the social and sensory challenges they may face, but also the stress and anxiety that come along with it. Differences need to be compensated for in the educational setting. Schedules need to be amended to offer educational support as well as the social and environmental support provided. High importance should be placed on understanding the link between academic learning and social/emotional competence. A lack of social and emotional competence can lead to a decrease in a student’s connection with school, and can also affect their academic performance. This reinforces the notion that social and emotional competence plays a vital role in learning, behavior, and academic engagement. With schools having such data-driven accountability regarding attendance and a heavy focus on academic aspects of the curriculum, social and emotional learning becomes overshadowed. The fact that all students go through the same middle and high schools with no adapted curriculum to meet the needs of students with disabilities is out of date.

Access to medical and educational services are critical. Federal and state governments are making cuts to regular and special education as well as early intervention and medical assistance with little regard to the increase of children who need these services. These services are essential to those who seek to have a higher education, the outcome of their future, and their overall quality of life. Many autistic children and adults rely on medical assistance for their healthcare services. School choice for children with autism is limited- the majority of private schools do not allow children with disabilities unless they are specifically serving to children with disabilities. This means that public schools need to fix and fund special programs.

With much of the focus on children with autism, light needs to be shed on what is happening to autistic adults. ⁶Access to employment is an example. 35% of people diagnosed with autism in the US cannot find a job. In June 2014, only 19.3% of people with disabilities in the US were participating in the labor force-- working or seeking work. Of those, 12.9% were unemployed. ⁷Unemployment among people with autism is currently at approximately 90% (of these, 85% are college-educated students), and at least 500,000 more people with autism will enter the workforce in the next decade. A major reason why employers do not hire people on the

⁶ Bureau of Labor Statistics 2014

⁷ Amy Conn, marketing director of Integrate

spectrum is largely due to prejudice. Managers of companies should be more educated about the autism spectrum and hold seminars on creating inclusive communities in the workplace, as well as handling different workplace scenarios. Changing the interview process is an important first step. Video and working résumés in which an applicant talks or demonstrates their skills on video is a way in which companies can help, and it allows employers to see potential candidates in a new light. Many adults with autism go to college and have skills that are in high demand by employers. Jobs that people with autism can fulfill include being a medical laboratory scientist because this job focuses more on technical skills rather than social skills. Other jobs that fit this bill are: computer programmer, reference librarian, engineer, accountant, and physician. Jobs in IT are especially growing, and many people on the spectrum are more than capable of filling these positions due to their abilities to pay close attention to detail.

Once the select few people with autism are hired, it becomes difficult for the person to break through without support due to the fact that many work environments rely heavily on social and communication skills. It is important to train managers, coworkers, and supervisors to support their skills. This training can help them understand their colleague, how to support them, and how to effectively communicate with them. This will allow people practice issues they may not have faced before. For employees on the spectrum, it is important to receive on the job training on communication and other social skills. This will allow them to better adjust to their new environment. This can include having a mentor to provide them with a role model to learn soft skills from. People with and without autism should have the same rights and punishments included, and it is important to find a balance between highlighting a person's challenges with autism and giving them "special treatment." Companies are beginning to learn that it is more likely for a productive work environment to occur when it is adjusted to suit the employees, rather than the employees having to adjust to suit the work environment. This is beginning to happen in Silicon Valley, and benefits are being noticed. Autism as an identity is something the general public is perhaps not as familiar with. One cannot be separated from their neurology. Autism is not a disease or an illness, and it cannot be removed or cured. It is an integral step for society to learn to accept people as they are and to put an effort into fostering inclusive environments. Both the public and private sector need to work together- the more companies and organizations that join to support this topic, the better the understanding and practices for people with autism and their peers will be.

A specific example on how society can slightly alter to be more accommodating is with fluorescent lighting. The subtle flickering and humming noise that these lights emit can be uncomfortable and even painful for person with autism. While everyone is doing what they need to do, a person on the spectrum may be struggling to even be in the room. The same goes for noise levels around cubicles. The chattering, sound of phones ringing, and other noises can bombard an autistic person with an overload of sensory input. For example, my cousin, James, finds it very difficult to be productive in a place in which cell phones are ringing, the lights are bright and humming, crowds form around where he works, and where people are chatting. All of the noises combined are stressful for him, and the same goes for many, many other people with ASD. It is important for people with autism to receive the accommodations that will help with their productivity. When buildings are designed nowadays, a lot of thought goes into making them accessible for those with physical disabilities. Hopefully, through increased knowledge and awareness, the same care and attention will go into creating accessible work spaces for autistic employees.

In the UK, supermarket retailer ASDA recently hosted its first “quiet hour:” a morning dedicated to silent shopping. All televisions, escalators, and in-store music was silenced- things that are primary causes of sensory overload. One of the most common places in which sensory overload occurs is in super markets, making it difficult for people with autism to do what the rest of society can do without a second thought. Toys R Us UK hosted a nationwide event for families with autism, in which they dimmed the lights and silenced the in-store music, and dedicated areas of the stores to be completely quiet. The initiative of the event was to provide an opportunity to children with autism and other differences to enjoy the festive shopping experience in the lead up to Christmas. In 2016, Microsoft announced a collaborative project with Danish specialized employment agency, “Specilisterne,” to expand its efforts in hiring people who have conditions which place them on the autism spectrum. The increased ability to retain information, the ability to see with a greater level of detail, to speed through technical or mathematical work at increased speeds and other unique skill sets have benefited the company, says Microsoft. Simple changes like this make a huge difference, and these major retailers hope that more companies will follow these great examples.

As an individual, in order to help to create a more inclusive society, I need to make people more aware of autism and to educate them on things we can do. For example, I can contact local supermarkets and other stores and explain how to make their establishment more inclusive to the autistic community by informing them on what other places have already done, for example getting rid of fluorescent lighting and creating a quiet hour. I will contact schools and explain simple things that can change, such as schedules. By taking little steps one at a time, a large change can be made.

There are many benefits of neurodiversity in the workplace. People on the spectrum demonstrate trustworthiness, strong memories, reliability, adherence to rules, a direct communication style, and keen attention to detail including pattern recognition. Beyond specific job skills, businesses and organizations are increasingly recognizing the importance of neurodiversity to innovation. JPMorgan says that, “autistic workers took just three to six months versus the usual three years to do the same level of work in its Mortgage Banking Technology division. They were also 50% more productive.” In fact, neurodiversity is especially important for innovative decision making, due to the ability to think outside the box and be extremely creative. A corporation that values inclusivity recognizes that people with different skills, backgrounds, experiences, and attitudes can bring fresh ideas, interpretations, and approaches to the table. Having brains in the workplace that are predisposed to certain strengths that not everyone has is an additional way to make a company or business successful.

Autism, in its totality, is simply another way of processing information. There is not much doubt that ASD is beginning to become accepted as part of the human fabric. Though it remains arcane, modern culture is beginning to be defined and influenced as people’s willingness to celebrate and better understand people who look, think, and act differently. However, it would greatly benefit the autistic community by continuing to amend society to be more inclusive. For example, in recent years, society has begun putting much more thought into those with physical disabilities by making places wheelchair accessible. If this much care was put into those with mental “disabilities,” everyone will see a benefit, neurotypical people included. Neurotypical people, in order to create a more inclusive and beneficial society, can continue to make changes such as “quiet hour” in supermarkets and removing fluorescent lights from places such as educational and work settings as well as stores that are easily accessible to the general

public. These little changes are a large step. We must learn from each other and work to amend school and work settings to fit the needs of everyone, and when hiring people, remind ourselves of the benefits of neurodiversity. If neurotypicals and people on the spectrum work together to make these changes, society as a result will be a more inclusive place for all. This inclusive society allow us, as humans, to reach unity through our differences. We will also unite our efforts to improve the world. Once we get past the division in the world by more communication between different groups of people, lots of energy and time will be saved. Society will benefit from different perspectives. New layers of understanding will enrich the world. By accepting diverse minds, we will gain intimate insights into the lives and challenges of other people, which opens the door to empathy and understanding. We will create a world with beneficial alliances and mutual cooperation.

Bibliography

AsapSCIENCE, director. *Debunking Anti-Vaxxers*. YouTube, 15 Feb. 2018, www.youtube.com/watch?v=b03U6BYF9L0.

“Autism (Autism Spectrum Disorder).” *American Speech-Language-Hearing Association*, ASHA, www.asha.org/public/speech/disorders/Autism/.

Autism Europe. “Fostering a Barrier-Free Society for People on the Autism Spectrum. *“Testimonies Collected within the Framework of the World Autism Awareness Day Campaign “Break Barriers Together for Autism – Let’s Build an Accessible Society,”*” 2 Apr. 2018.

“Autism Spectrum Disorders—A Genetics Review.” by Judith H Miles. *Genetics in Medicine*, vol. 13, no. 4, Apr. 2011.

Ben-Avie, Michael, and Office of Assessment. “How Can We Help Young Adults with Autism Thrive in the Workplace?” *The Conversation*, 10 Apr. 2018, theconversation.com/how-can-we-help-young-adults-with-autism-thrive-in-the-workplace-5648.

Grandin, Temple, director. *The Autistic Brain*. *Chicago Humanities Festival*, YouTube, 19 Nov. 2013, www.youtube.com/watch?v=MWePrOuSeSY.

Harris, John. “Working with Autism: 'We Need People Who Dare to Think Differently'.” *The Guardian*, Guardian News and Media, 9 Oct. 2017, www.theguardian.com/society/2017/oct/09/autism-working-spectrum-capable-employees-talent.

Helen V. Ratajczak (2011) Theoretical aspects of autism: Causes—A review, *Journal of Immunotoxicology*, 8:1, 68-79, DOI: 10.3109/1547691X.2010.545086

Ileal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children.

“Living with Autism.” *Autism Society*, www.autism-society.org/living-with-autism/.

Natalia Gumińska, et al. “People with Autism in Society – Challenge of 21th Century. Case of Poland.” *Science Direct*, Elsevier, https://ac.els-cdn.com/S1877042815006370/1-s2.0-S1877042815006370-main.pdf?_tid=efc1c177-6154-4707-8a2f-7fff6d26c8d6&acdnat=1523734474_961b46b6b77de1a9d90b21d1be8126f2.

“New Government Survey Pegs Autism Prevalence at 1 in 45.” *Autism Speaks*, 14 Nov. 2015, www.autismspeaks.org/science/science-news/new-government-survey-pegs-autism-prevalence-1-45.

S, Eva, and Maye. "The Importance of a Diverse and Inclusive Society." *The Dream Catcher*, 25 Aug. 2017, thedreamcatch.com/importance-of-a-diverse-and-inclusive-society/.

"TEDTalks: Temple Grandin--The World Needs All Kinds of Minds." TED, 2010.

"The Autistic Brain." *Cambridge Neuroscience*,
www.neuroscience.cam.ac.uk/research/comeos/AutisticBrain.php.

UC Davis Health, and Department of Public Affairs and Marketing. "Discovering What Is Different about the Autistic Brain." *Discovering What Is Different about the Autistic Brain: UC Davis Health System Feature Story*,
www.ucdmc.ucdavis.edu/welcome/features/20060726_amygdala/.

U.S. Bureau of Labor Statistics, U.S. Bureau of Labor Statistics, www.bls.gov/home.htm.

"What Is Autism?" *Autism Society*, www.autism-society.org/what-is/.

Won, Hyejung, et al. *Frontiers in Molecular Neuroscience*, Frontiers Media S.A., 2013,
www.ncbi.nlm.nih.gov/pmc/articles/PMC3733014/&sa=D&ust=1523823466200000&usg=AFQjCNGL0hZMzn_9sUis7ZSt1TGMBMbmV.