

# Welcome to the Autistic Community!



*Above: An illustration by Anabelle Listic. A hand is drawing a line of green dots on a tablet screen. Both the tablet and the illustration have abstract blue backgrounds.*

A Project of the Autism NOW Center and the Autistic Self Advocacy Network



**Welcome to the Autistic Community!**

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**The Autism NOW Center is a repository of resources and information about Autism Spectrum Disorders and other developmental disabilities. They work to create and disseminate dynamic, interactive, and accessible information products to people with autism and their families, as well as to other key stakeholders.**

**The Autistic Self Advocacy Network (ASAN) is a nonprofit organization run by and for Autistic people. ASAN was created to provide support and services to individuals on the autism spectrum, while working to educate the public about autism. They work in public policy advocacy, community engagement and culture-building, research, and education to these ends.**

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## How to Use This Book

Everyone is different, and sometimes people are born autistic. The first thing you must know is that autism is not a bad thing; you are not sick or bad. You are just different, and that is good.

This book will help you to learn about autism. It will teach you what it is and how to live with it. Being autistic is not bad, but it is also not easy. You will learn as you grow up that you think and act differently than your friends. You might not understand something when others seem to. It's possible you might even feel a bit embarrassed because of it.

Well, don't worry. This book will not only tell you what Autism means, but it will also help you learn how to include it into your daily life.



Autism is not a sickness, or something to be cured. It is a part of you, and it will be for the rest of your life. But being autistic just means you look at the world differently. You are the only one who can decide what it means for your future - but it never hurts to ask for help.

# What Is Autism?

Everyone's brain works in a different way. The way our brains work is called "autism." Every autistic person is different, but we are also like each other in many ways.

For some of us, the way we see and feel things is different from many other people. Sometimes things are too much: things can be too loud or too bright. Sometimes things are not enough: things can be too quiet or hard to see. There are lots of ways things can be too much or too little. Sometimes we don't like the things that other people like and that's OK.



The way we move is also different. Sometimes we do the same things over and over. Sometimes we can only move a little. Sometimes we have a hard time moving at all and that's OK.



The way we use words can be different too. Some of us don't say words at all. Some of us only say words sometimes. It can be very hard to say words. It can also be hard to hear words. Sometimes it's easier to say things we've heard before, but there are lots of ways to say things without using words. People can say things with sign language, by drawing or pointing to

pictures, with an iPad, or with sounds that are not words, and that's OK.

The way we think can be different. Sometimes we think a lot about things we really like. Sometimes we think a lot about bad things. Sometimes it's hard to think about other things. We also can take a while to get used to new things. That makes it hard when things change.

All of these things can make us different from other people. It can be hard to understand other people. It may be hard for people to understand us. It may be hard to make friends or do things with lots of people. But, we can explain how we are different so other people understand us. "Autism" is a

simple word that describes how we are different. The word “autism” helps non-autistics understand us better.

## What Does It Mean?



Being autistic means that you see the world in a different way than most people do. Things that make sense to you might not make sense to them. Things that make sense to other people might not make sense to you. You might notice certain things that most other people would miss, such as quiet noises, patterns in complex shapes, or the solutions to math problems. You might miss certain things that most other people would notice, such as recognizing faces or body language

You might like to play in a different way than other people do. You might enjoy sights or sounds or textures that other people think are boring. There

may be some kinds of sights, sounds or textures that really bother you, which other people don't seem to mind or even notice. Sometimes people might not understand how or why a sight, sound or texture is bothering you.

Sometimes your different way of seeing the world helps you solve problems quickly or more thoroughly. Sometimes it will take you longer than others to do things, like tie your shoes or make food. And sometimes other people will try to tell you that your way of seeing things and doing things is wrong.

All of these differences can make it hard for you to understand other people, and hard for them to understand you, especially if they don't know about or understand autism. Sometimes people will try to make you see or do things their way, instead of trying to understand the way that you see and do things. They won't understand that you need to do things in your own way. Their way won't work for your brain, just like your way wouldn't work for their brain. It can be very upsetting when people try to force your brain to work differently!

Being autistic means that you will have to find your own way of doing things. It means that sometimes you will have to defend your right to do things in the way that works for you. When you can find ways to let the people around you know what you need, and when they understand and respect your needs, that can give you the chance to show them your own way of doing things. And sometimes, your autistic way of doing things will turn out to be the best way to get something done. Sometimes, being autistic will mean that you are the best person for the job!

## Am I Disabled?

Yes, in today's world, autism is a disability. It is a disability because most people don't understand autism very well yet, and the world is set up for non-disabled people. Some places are too loud and bright and noisy for autistic people, without calm, quiet places for us to go rest when we need it. Some people don't understand why we move or speak or act differently. These are examples of how society disables autistic people.

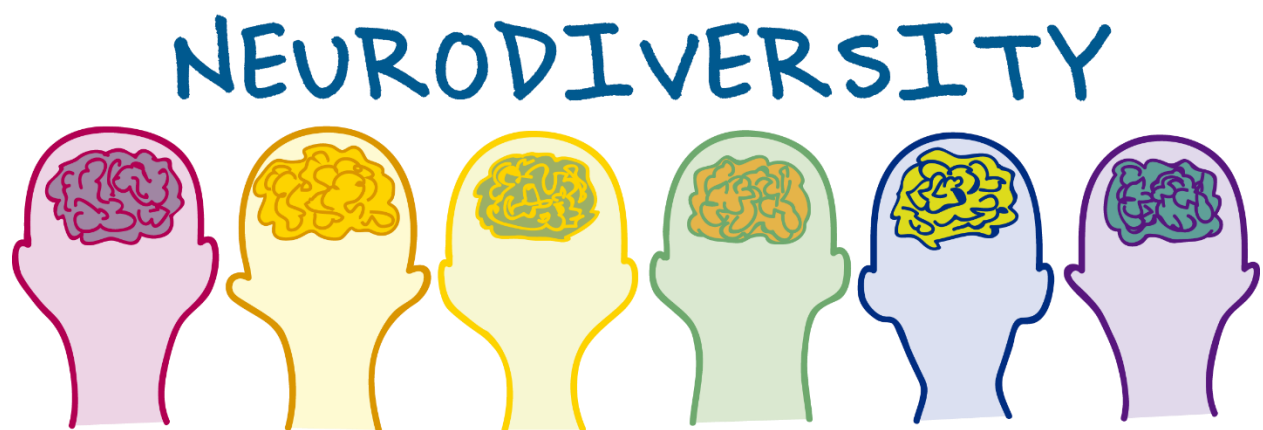
A disability is something that society creates, by not having support for some kinds of people. Society *disables* people who use wheelchairs, when buildings have stairs but no ramps or elevators. Society disables deaf people, when instructions for things are only spoken and not written down. Society disables blind people, when instructions for things are only written down and not spoken. And society disables autistic people, when they don't give us the supports we need to go places and do things.

Deafness wouldn't be a disability if most people were deaf and only a few people could hear, because everything would be set up for the deaf people. Things would be written down instead of spoken and most people

would know sign language. People who could hear would be disabled if deaf people didn't support them by not making really loud noises.

If most people had no legs and used wheelchairs, then everyplace would have ramps instead of stairs, and everything would be designed for people without legs. People who had legs would be disabled in that world, because they couldn't fit into small spaces that were designed for people without legs.

Disability is something that the rest of the world does to people whose bodies or brains are different in a way that they don't support. Autistic people are disabled by a world that isn't set up to support autistic people. This doesn't mean that autistic people are damaged or broken. It means that we're different in a way that the world doesn't have built-in support for.



Even though autism is a disability in today's world, we can make life easier by setting up our own spaces to support the way our brain works. The people closest to us can make our lives easier by learning about our autistic differences and about how to do things that help us and how to not do things that are hard for us.

Things may get harder when we have to go out places such as school, the store or the airport – places with lots of people and noise, but when we have enough support in our homes and with our friends and family, we can make it harder for the rest of the world to disable us.

# Am I Okay?

AM I OKAY? AM I REALLY *THAT* DIFFERENT?  
SOMETIMES I STRUGGLE. DO OTHERS STRUGGLE?  
WEAKNESSES? STRENGTHS?  
EVERYONE HAS THEIR  
STRENGTHS AND  
WEAKNESSES.  
WHAT MAKES ME  
DIFFERENT? ARE  
THERE OTHERS  
LIKE ME? I  
WANT TO BE  
ME, AND FIND  
WHAT WORKS  
FOR ME. I AM  
UNIQUE, AND  
THAT IS OKAY. I  
MAY HAVE  
DIFFERENT NEEDS, BUT I AM NOT A BURDEN.



I am autistic. I look like everybody else. I think differently compared to others. I may think slower or quicker than others, but I'm okay.

Everybody is good at some things. For example, I like math and art. Everybody needs help with some things. For example, I need help with reading and sports. Autistic people are good at some things but have to work harder at others, just like everybody does.

Many autistic people also have “sensory processing disorders.” This means that while some autistic people hate feeling, seeing, and hearing some things, we enjoy other sensations, sights, and sounds more than non-autistic people do.

Many autistic people “stim” in ways that other people do not. “Stimming” means doing things with your body to relax or to show your feelings – for example, some autistic people rock back and forth or flap their hands, and this is stimming.

Autistic people can be different from other people in these ways and many more. We have some different ways of being and thinking, and some different needs, and that’s okay.

## More Alike Than Different

Many Autistics may seem different than other people, but we are actually more similar than you might think. Autistic people can have the same hopes, dreams, wants and needs as others. Sometimes we have the same interests as “non-Autistic” people. But sometimes, there are a few differences between us and others.



Autistic people have some of the same hopes and dreams as non-Autistic people. We may want to go to college, to have a job, or to live on our own.

Autistics sometimes need help from others, either in familiar ways (like needing help to reach a high shelf) or unusual ways (like needing help from an iPad to speak). Autistic people want respect, too, like everyone else.

Autistic people sometimes share our interests. Some Autistics enjoy arts and crafts, writing, fashion, riding bikes, dancing, or swimming. Autistics can also prefer one subject, the same way non-Autistic people do, but sometimes more so.

What things do you NOT have in common with most non-autistic kids? Here are some of the uncommon things that keep us apart from the rest of the group. Sometimes, an autistic kid might feel like it's hard for them to join in playing with other children and/or have conversations with large groups. Another thing that can be difficult for Autistics is learning to understand jokes, sarcasm, and "figures of speech" – Autistic people are more likely to think something is a joke when it's actually serious, and are more likely to take jokes literally.

There can be a lot of things alike between kids who are non-Autistics and others who are Autistic. There can also be things that make us different from each other. Non-Autistics and Autistics alike can have the same or similar goals, dreams, wishes, or hopes as each other. Just because Autistics are different does NOT mean that we are "abnormal". We are simply another kind of normal.

## Positives

Being autistic is not always easy. Sometimes, sights or sounds are too intense. Other times, being in groups of people can be really scary. However, even though autism can make some parts of life harder, it can make other things wonderful!

Autistic people think about things in different ways than other people. We can see things that people without autism rarely notice. This is good, because people with different ways of thinking can work together to make positive changes in the world.

Autism is another way of thinking that can be used to make the world a more beautiful place. For example, I think being autistic lets me think ideas through more thoroughly. Contrary to popular belief, many autistic people learn empathy and compassion *because* of our autism and not in spite of it.

In medical terms, autism is a “neurological disorder.” This means that autistic minds are unusual. Our brain cells connect to each other in different ways compared to non-autistic brains. In other words, being autistic affects

how we experience everything. We learn, see, and have feelings in ways that most people do not.

For example, I like the feeling of soft fabrics touching my skin – it's exceptionally pleasing. I am also able to listen to music and let it play over unpleasant noises, which help me turn my attention away from stressful situation. Some autistic kids also like specific things a lot: these things can be flavors, smells, sights, touches, or sounds. Because of this, some autistics enjoy and experience things that other people rarely notice.

Lots of autistic kids have “special interests”: this means that they have a really big interest in a topic. For example, I love gymnastics. I enjoy watching it, but I also like learning facts about it and learning how the sport has changed over time. I also like learning about the best gymnasts who have ever lived. I love gymnastics, and have a very heightened focus on it. That's because I am autistic.



I wish when I found out about my autism diagnosis I knew there were good things about being autistic. I wish I knew that being autistic allows me to see things differently, and that this difference is good. I wish I knew that my “nervous habits” were just things I did to calm myself down. I wish I knew that being autistic gave me my passion for gymnastics. I wish I was able to be happy I was autistic from the very

beginning, and that is why I want to help people who read this do the same.

## Am I The Only One?

No, you're not! Lots of people are autistic. Some of them may not be diagnosed yet, and some may choose to keep it to themselves, which is why it might seem like you're the only one right now. But in your life, you will probably meet many other autistic people.

Some autistic kids feel bad about being autistic, because people have negative ideas about autism that aren't true. Some autistic people are scared to tell because they worry they might get bullied, and because some people think (incorrectly) that autism makes people dangerous. Some kids' parents tell them not to tell because they are embarrassed or because they are worried they will be hurt.

Some kids don't know they are autistic yet. Some people think that autism affects boys more than girls, so many autistic girls don't get the right tests until they're older. That doesn't make them any less autistic, it just means they don't know that yet. They may be confused

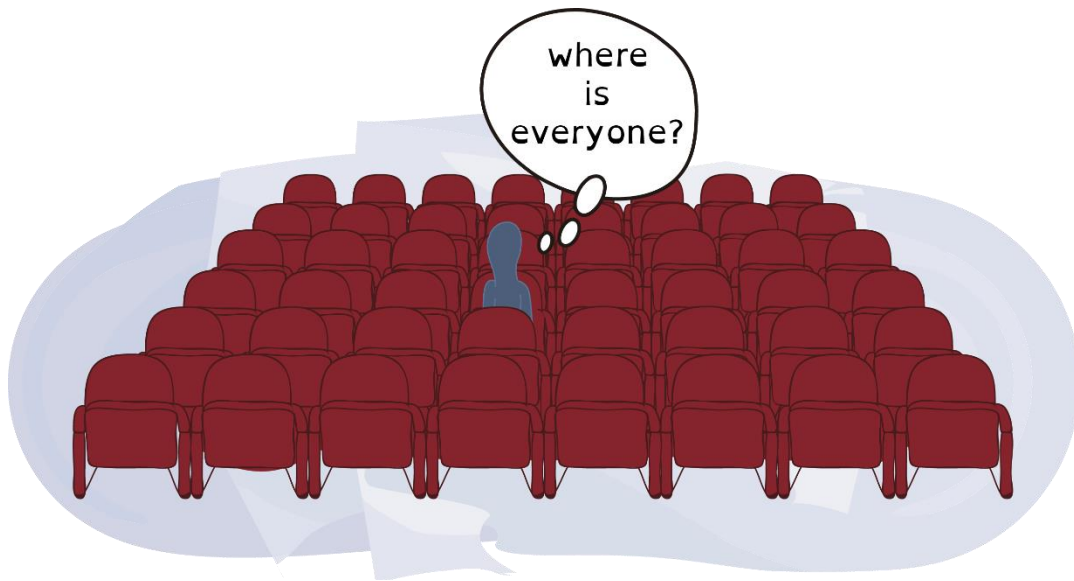


about the way they behave or why they are different. They probably feel like you did before you found out.

Some autistic kids don't go to typical school. There are special schools and programs for autistic kids, although not all autistic kids use them and not everyone agrees that they are the right thing. So even though as many as 1 out of 50 kids may be autistic, you may feel that you are the only one.

There are lots of autistic kids out there. You may already know some, and even if you don't, you'll probably meet some in the years ahead of you. You are not alone.

## Where Are The Other People Like Me?



Other autistic people are everywhere! There are many young autistic people like you: currently, we think that there may be one autistic person for every fifty non-autistic people. That means that a few kids in your school or around your neighborhood might be autistic, too.

Autistic people sometimes don't like to talk in person too much, so we use the Internet a lot to talk to each other. Ask your parents to help you find online autistic space, or a meet-up group posted for autistic kids, if you're interested in that.

And autistic adults are everywhere, too. The TV and magazines don't talk about that as much, and we don't really know why. But there are just as many autistic adults as there are autistic kids, because autistic kids grow up to be adults. Your teacher, the clerk at the grocery store, someone you walk past on the street, somebody in a restaurant - these people might all be autistic. The only way you can find out is if someone decides to tell you, but you are definitely not alone.

## What Are My Rights?

There are several laws that protect your rights in school and in the wider world. Laws cover your rights in school, at work, and in your search for a home. While your focus as a youth is on school, the law protects you from mistreatment in many places outside of school as well.

It is your right to be treated with the same respect as every other student at your school. Because you are autistic, you have unique challenges in your education, from just completing the school day to getting the best grades you can. Your teachers are required to help you meet these challenges.

An Individualized Education Plan, also called an IEP, is an agreement between your parents or guardians and the school. Your IEP is a plan designed to help you in school. This plan sets goals for your education, which teachers will help you to reach.

“Accommodations” are extra things that help you in the classroom. This help could take the form of extra teaching, more time on tests, a quiet study area, or other help. The accommodation doesn’t mean you don’t have to

learn, and it doesn't change your assignments; it just gives you extra help.

To get accommodations, you must first make others aware of your need for help. If nobody else knows about your challenges, they can't make accommodations. You could tell your teacher, or your parents or guardians, and have them arrange a meeting with the principal to talk about accommodations or an IEP.

If a teacher is not accommodating you, you should tell your parent or guardian. They can help you to talk to the principal about your challenges. If problems continue, the adults in your life should know about it so they can consider further action.



## Resources



Sometimes, you might run into problems that have to do with being autistic. For example, at school, your teacher might not want to follow your IEP. Or someone might be making fun of you. If your parents don't believe you're autistic, they might expect you to do things the same way as everyone else. This can cause problems for you.

But, you don't have to deal with problems like this alone. There are a lot of resources you can use to get help.

Your school's guidance counselor might be a good place to start, if your parents can't or won't help. It's the counselor's job to help students with their problems. They might not know a lot about autism, but they will

understand if you are having problems with a teacher, or with someone making fun of you or treating you badly. They will be able to suggest some ways you can handle people without getting hurt or upset.

If the problem is that someone is making fun of you, it might be helpful to look at the website: <http://www.stopbullying.gov/>. They have pages for kids and teens, and you can look at it to learn about bullying and what to do if someone is bullying you. The website doesn't talk specifically about autism, but it talks about kids who might act or think differently from other kids, and how sometimes they get made fun of.

For problems involving adults, there are organizations that are set up specifically to help autistic people fix situations they can't fix alone. Autism NOW (<http://autismnow.org>) is a website about how autism affects all areas of life, from being a kid to a teenager to an adult. The Autistic Self Advocacy Network (<http://autisticadvocacy.org>) has chapters that are all over the country, and one of those groups might be able to help you with your problem.

Another resource is your state's Developmental Disabilities Council (DDC). You can find your council online at <http://www.nacdd.org/about-nacdd/councils-on-developmental-disabilities.aspx>. The DDCs exist because even though there are laws that are supposed to give people with developmental disabilities the same rights as neurotypical people, the laws don't always get enforced. The state councils are a voice in state government to advocate for policies to promote self-determination and inclusion for people with intellectual or developmental disabilities (like

autism), and their families. The DD councils were created so they could help people with developmental disabilities, so if you need one, don't be afraid to ask for help!

The Protection & Advocacy system also exists in every state to help people with developmental disabilities. They provide legally based advocacy services to people with disabilities and in some cases, can provide a lawyer or another kind of representative if you have to go to court. They also work on making sure those with developmental disabilities have full access to things like education and healthcare – basically, helping to change the system. They have an information page you can look at on the National Disability Rights Network website: <http://www.ndrn.org/en/about/paacap-network.html>.

The best line of defense if you are having problems will usually be your parents – they can speak up for you in almost all situations. But if you can't look to your parents or other family for help, these websites and advocates are going to be some of the best people to help you with your challenges.

## What Does My Future Look Like?

H.O.P.E.

No one can predict the future. However, there are a few things you can do to help create the best future for *you*.

Here are some ways to make a bright future with ***H.O.P.E!***

Be ***H***onest.

What do you want your future to look like? Here are some questions to help you think about that.

- Do you want to get good grades in school?
- What would you like to learn about?
- Is math difficult for you?
- Do you want to become a scientist in the future?
- Do you like to work with animals?
- Do you want to learn how to make new friends?

People will understand you better when you communicate to them what you want and what you need. Some autistic people communicate by talking. Some communicate by using hand signals, drawing, or writing.

Which way works best for you? Just do your best. When others understand you better, they can be better friends and help you to reach your goals!

Be **O**bservant.

To be *observant* means to pay close attention. In this case, it means that you should pay close attention to how you feel.

When you feel good, ask yourself, “*What is working for me right now?*” Perhaps you are really happy drawing, or you’re wearing a favorite shirt.

When you are feeling overwhelmed or frustrated, ask yourself, and/or “*What is not working for me right now?*” The loud motor of the vacuum may bother you. Perhaps you are hungry.

***Exercise for your 5 senses:*** Stop, take a breath, and silently ask yourself:

- Hearing: is this music too loud for me?
- Sight: is the flickering light distracting me from my schoolwork?
- Taste: does eating too much sugar make me feel anxious?
- Smell: is the smell of the teacher’s perfume bothering me?
- Touch: is this shirt making my skin feel itchy?

Knowing *what works* and *what does not work* for you is important for your own happiness now and in the future.

Be **P**repared.

Be prepared to care for yourself when your environment isn’t working for you.

- Keep earplugs handy for noisy situations

- Ask your teacher if the flickering light can be replaced
- Ask to have healthier snacks
- Wear your favorite comfortable clothes
- Ask for help

Being well prepared for unexpected events will make life easier and more fun.

### **Empower Yourself.**

What are you really good at? Drawing? Reading? Writing? *Do it!*

Do your best in the subjects you like most. Don't be afraid to ask for help in the ones you need help with. Remember your strengths. Use them and feel good about them. Be proud!

So, remember to:

- Be **h**onest about your needs and wants.
- Be **o**bservant of *what works* and *what doesn't work* for you.
- Be **p**repared to care for yourself during unpleasant events.
- **E**mpower yourself by remembering and building up your strengths.

Living with **H.O.P.E** can make your future bright as the stars in the sky!



## Glossary:

Neurotypical: A person is *neurotypical* (NT) if the way her brain works is basically the same as the majority of people around her, or is regarded as more or less “normal” by the standards of the society she lives in.

Neurodivergent: A *neurodivergent* person is someone whose brains functions in some way that is significantly different from the brains of the majority of people in their society.

Overstimulated: When someone senses something that is too much, or very unpleasant – like a bright light, a disgusting smell, or a repetitive noise – they can become *overstimulated*. This means that they have trouble focusing on other things, because the experience is too attention-catching.

Stimming: *Stimming*, short for *self-stimulatory behaviors*, is something everybody does. To *stim* means to do something with your body because it feels good, is calming, or makes it easier to focus on other things. Some common *stims* include tapping your feet, feeling your face or head, and flapping.

Understimulated: When someone is not experiencing enough sensory input – when they are not seeing, smelling, hearing, tasting, or touching enough things – they can become *understimulated*. This means that they have trouble focusing on other things, because they are bored or unhappy.

## Contributors:

Iliana Rotker-Lynn

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**Iliana Rotker-Lynn** is a senior at the University of Wisconsin-Madison with a double major in Theater and Women's Studies. She was diagnosed with Asperger's Syndrome in middle school but prefers to identify as simply being on the autism spectrum. She enjoys theater, dance, writing, and playing with her cats.

**Jessica Hatch** is a philosophy major at Tulane University. She was diagnosed with autism as a child.

**Lucas** is a student at the Macaulay Honors College at Lehman College majoring in Computer Graphics and minoring in Japanese. He was diagnosed with Autism in infancy. He was a participant in the first Autism Campus Inclusion project.

**Marcie** has been involved with the on-line autistic community since 2003 and is a two-time presenter at Autreat. Her interests include natural history, neuroscience, gardening, and cats.

**Madeline Jarboe** is an LGBTQ and disability activist who lives in Tucson, Arizona.

**Anabelle Listic** is an autistic freelance graphic designer, professional photographer, artist, and visual accessibility advocate. She creates stylish, functional advocacy and life tools for autistic, visually inclined, people who are searching for creative, quick, alternative ways to communicate. Anabelle is also a mentor, blogger, and has a video series encouraging stimming, titled "Way To Stim Wednesday". She works to be a part of positive change to help make this world a more accessible, visual, sensory friendly place for autistic people. You can visit Anabelle's website, [anabellelistic.com](http://anabellelistic.com) to learn more.

**Connor Haas** is a 22 year old fifth year senior at the University of Wisconsin-Madison, majoring in history and political science. He was diagnosed with Asperger's as a young child and has other people in his family with autism. Connor interns for a United States Senator for the state of Wisconsin and his interests include politics, sports, weight lifting, and playing guitar.

**Allison Kimball** is a 16 year old sophomore in high school. She was diagnosed with Autism when she was 3 years old. One of the things that set her apart when she was younger was the fact that she barely spoke, but could hear every word spoken. Now she loves to write because it helps her understand and imagine what happens in the real world around her "NOW"!

**Catherine M.** is a married ex-doctor and social worker with a cat. She figured out she had autism while she was reading about her nephew's diagnosis. Autism made sense of past relationship struggles and the loss of her profession due to not being able to deal with workplace politics.

**Nathan Goodman** is a senior fellow and Lysander Spooner Research Scholar in Abolitionist Studies at the Center for a Stateless Society. He is also an undergraduate who studies mathematics at the University of Utah. Nathan was diagnosed with Asperger's as a young child.

**Justin McLaughlin** is a college graduate with a Bachelor's Degree in Journalism from the University of Wisconsin-Oshkosh. He is still looking for work, preferably in the journalism field, but for now contributes work to

ASAN. He was introduced to ASAN by a family friend who runs a local autistic support group.

After being diagnosed with Autism in 2003, **Hayes Kaufman** has made great effort to involve himself in the Autistic community and to be a source of advocacy for those still struggling with their own diagnosis. He considers his Autism a strength and hopes to one day be able to successfully combine it with his professional life. Working with the Autistic Self Advocacy Network has only helped to further that goal.

**Brandy Nightingale** was diagnosed with Asperger's Syndrome, an autism spectrum disorder, in 2010 at the age of thirty-five. An entrepreneur, visual effects coordinator on feature films, retired stand-up comedian, and writer, she recently penned a book, *Everything's Hunky Dory: A Memoir*, and resides in beautiful Ojai, California with her husband, three rescued dogs, and two happy hens.

**Samantha Lee** was diagnosed with PDD-NOS when she was three years old. She is currently a junior at Auburn University pursuing a degree in Biomedical Sciences with minors in Spanish and Psychology. In the future, Samantha hopes to become a pediatric occupational therapist who specializes in working with children with developmental disabilities.

**Matt Young** is an Autistic adult originally from Davis, California and now living in Seattle, Washington. He was diagnosed in adulthood, in 2005, and found tremendous support and community through the neurodiversity movement. He currently serves as chapter leader of the Washington State Chapter of the Autistic Self Advocacy Network.