

The Neurotypical Parent's Autism Advocacy Toolkit

A beginner's guide to helping parents model autism acceptance and advocacy



The Importance of Advocacy and Self-Advocacy

It's clear you love your child and want the best for him or her. You wouldn't be reading this if you didn't care deeply about your child's future and livelihood. This guide will help you reflect on the following questions: How does your love for your autistic child manifest itself? What are your beliefs about autism? How can you offer your autistic child the best opportunities to succeed?

Some parents unknowingly adopt an agenda for their autistic children that their children never internalize. Parents may push their children toward certain careers or activities they think will help them, pursue aggressive therapies, and try every new medicine or autism "treatment" on the market.

Unfortunately, treating autism as a nasty disease that needs to be fought off in order to live a happy, productive life can have a devastating impact on a child's perception of self-worth. Fortunately, while we may not be able to control autism, we can certainly control our attitudes about it. **Autism advocacy beings with love, acceptance, and respect for your child as an autistic being, not someone who is trapped inside of an autistic body.**

Quotes

"We must always take sides. Neutrality helps the oppressor, never the victim. Silence encourages the tormentor, never the tormented." -Elie Wiesel, author, professor, activist

"Independent living is not doing things by yourself. It is being in control of how things are done." -Judy Heumann, Special Advisor for International Disability Rights

"There needs to be a lot more emphasis on what a child can do instead of what he cannot do." -Dr. Temple Grandin, author, speaker, Animal Behavior Specialist

"It's not that I'm autistic that causes me problems; it's how people treat autistics. And that is a society problem, not a disability problem." -Lydia Brown
<http://autistichoya.com>

You are most likely interested in autism advocacy because you want to help your autistic child successfully navigate this world and offer him the support and tools to maximize his quality of life. To achieve these ends as a parent, it is important to both understand how to best advocate for your child and how to teach your child to self-advocate. This toolkit offers you useful information, resources, and tips to help you advocate for your child.

Participating in autism advocacy does not mean you work to eradicate autism. Disability advocates spend time working towards community acceptance and human rights equality rather than searching for "cures" or researching preventative measures. It is easy to get caught up in the "warrior" movement to "fight" autism because the media is most interested in representing it (causes, treatments, cures, and prevention). Unfortunately, not enough attention is paid to examining how autistic individuals live their lives, the challenges they face, and ways society can improve acceptance and their overall quality of life *now*.

Autism advocates support the creation of a society that acknowledges the civil rights of autistic individuals and offers them the same opportunities that neurotypicals have access to. This means you are encouraging others to embrace autism and change our culture and environment to make autism less disabling.

For further reading on advocacy: [*The Future \(and the Past\) of Autism Advocacy, Or Why the ASA's Magazine, The Advocate, Wouldn't Publish This*](#) by Ari Ne'eman of Autistic Self Advocacy Network

The Benefits of Teaching Self-Advocacy

Teaching your child to self-advocate is essential if she is capable. You will not always be around to advocate for your child, and it's important to help your child build the confidence she needs to learn, work, and live comfortably. Teaching self-advocacy skills offers many crucial benefits for children:

- It builds their self-confidence.
- It allows them to realize the power of positive thinking, making the most of their reality, and using their gifts to achieve their goals.
- It promotes peace and acceptance, teaching society to embrace disability and improve living for all autistic or otherwise disabled people.
- It helps them achieve varying levels of independence as they learn to communicate their specific needs and utilize their talents.



Some autistic people find peace and freedom through self-advocacy channels. Finding other individuals who either share their interests or struggles can help autistic people cope with the isolation or rejection they may feel on a daily basis. It is the work of self-advocates that has progressed the disability rights movement, and the more voices that are heard helps make more potential accommodations or cultural changes possible.

So What Exactly Am I Teaching My Child?

- How autism impacts how they perceive and interact with the environment
- What to disclose in different situations in order to achieve necessary accommodations
- How to identify and articulate their talents and strengths
- How to prepare for common life changes such as school and work transitions
- Information about their IEPs and The Americans with Disabilities Act (ADA) so they become familiar with their rights.

A Brief History of Autism Advocacy and the Neurodiversity Movement

Jim Sinclair first publicly articulated the anti-cure approach in the 1980s. He co-founded Autism Network International with Donna Williams and Kathy Grant, two other autistic advocates. Autism Network International published a regular newsletter written by autistic people that advocated for autism rights. The organization fought for a voice in the mainstream public discussion on autism. Jim Sinclair's writing exposed parents to an autism reality many had never before considered. In his groundbreaking article "Don't Mourn for Us," Sinclair argues that autism is *not* a tragedy, and that suggesting it is can seriously harm the confidence of autistic children. He writes:

"Autism isn't something a person *has*, or a 'shell' that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with... Therefore, when parents say, 'I wish my child did not have autism,' what they're really saying is 'I wish the autistic child that I have did not exist and I had a different (non-autistic child) instead.' This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure...that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces."

Sinclair goes on to suggest that the tragedy of autism is not autism itself or autistic identity, but rather how autistic people are treated by society. He urges parents to make the shift from focusing on the trauma of raising an autistic child to



teaching the world how to embrace autism and becoming an advocate for neurodiversity. Sinclair writes, "The tragedy is not that we're here, but that your world has no place for us to be."

In 1996, with the help of Sinclair, Autism Network International held its first Autreat, an annual retreat for autistic individuals that emphasizes positive autistic living rather than causes or cures for autism. Other disability rights organizations began forming to support the civil liberties of autistic individuals, including The Autism Acceptance Project (TAAP) in 2006 (founded by the mother of an autistic child and an autistic advisory and board) and the Autistic Self Advocacy Network (ASAN) in 2008.

The world first took notice of ASAN when their letter-writing protest successfully halted the "Ransom Notes" billboard campaign in New York City, which had suggested that autism was like a kidnapper stealing children from society. In 2009, the President of ASAN, Ari Ne'eman, was nominated by President Barack Obama to the National Council on Disability and helped advise Congress and the President on disability policy. Today ASAN participates in a wide range of advocacy work to inform policy makers and the general public about autism and encourage more autistic voices to be heard in the public conversation about autism.

Terms

"Autistic Person" vs. "Person with Autism"

Many neurotypical special education teachers or other professionals working with disabled people have been trained to use person-first language, meaning they've been led to believe that it is more socially appropriate and sensitive to emphasize a person's humanity before her disability. For example, they might explain that it is more appropriate to describe someone as "a person with autism," rather than "an autistic person." While these semantics may be appropriate for some disabled communities, many within the autistic community find this language offensive. This is because the separation of personhood with autism suggests that the autism is not a part of their identity, which many take issue with. Some people argue that the desire to separate their autism from their personhood suggests that it is an affliction they can (and should be) rid of and still maintain their true personalities. It leaves no room for pride in their differences or unique identity. However, these preferences are not universal, and it is best to respect the wishes of whomever you are speaking to or about.

Neurotypical

The term "neurotypical" technically refers to anyone with a typical neurology. This means a neurotypical individual would **not** have dyslexia, attention deficit hyperactivity disorder (ADHD), or bipolar disorder, for example. The autistic community has also adopted this term to refer to a person who is not autistic.

Neurodiversity

Neurodiversity is the concept that encourages the acceptance of a variety of different neurological conditions. It asks people to embrace neurological differences, treating everyone with dignity and respect. In general, this term can be applied to neurological differences such as ADHD, bipolar disorder, dyslexia, Tourette Syndrome, and autism spectrum disorder, among others. Among the autistic community, "neurodiversity" refers to the autism advocacy concept that treats autism as a neurological variation that should be embraced and supported, rather than a disease that society should eradicate.



Quotes

"Always remember that accepting autistic people does not equal accepting autistic suffering or disability. Many fine people devote their lives to relieving suffering in our population, whether through addressing medical issues like intestinal distress or by helping us make friends or find jobs. That work is an admirable accompaniment to acceptance."

-John Elder Robison, author

<http://jerobison.blogspot.com/>

"If I could snap my fingers and be nonautistic, I would not. Autism is part of what I am."

-Dr. Temple Grandin, Animal Behavior Specialist and author of *The Autistic Brain*

"Don't think that there's a different, better child 'hiding' behind the autism. This is your child. Love the child in front of you. Encourage his strengths, celebrate his quirks, and improve his weaknesses, the way you would with any child."

-Claire Scovell LaZebnki, author of *Growing Up on the Spectrum*

Terms Continued...

Ableism

Ableism is the discrimination of another person based on a disability. It is the set of beliefs that identify people as socially or morally inferior based on their physical, emotional, developmental, or psychological disability. Society's inferior treatment of autistic individuals, particularly the campaign to hide autism or eliminate all traces of it is a form of ableism.

Medical Model Vs. Social Model of Disability

The *medical* model of disability suggests that a person's disability is a problem that lies within the individual. The *social* model of disability suggests that disability occurs when a person's environment is not suited to him or her. For example, the medical model of disability would assume that a person in a wheelchair who can't access certain buildings is disabled because she needs a wheelchair to move around and can't get up the steps. The social model of disability would suggest that the stairs are the problem and that inserting a ramp would eliminate the disability in this situation.

Neurotypical Privilege

Neurotypical privilege refers to the ease with which neurotypicals navigate life because their society has developed accommodations that cater to most of their needs. It is difficult for many neurotypical individuals to truly understand the privileges they enjoy. Neurotypical privilege impacts the ease of daily living and long-term opportunities. *Square 8* is a blog devoted to disability that has a [detailed post](#) about neurotypical privilege with several specific examples.



Self-Advocate Blog List

The #ActuallyAutistic Blog List is an extensive list of Autistic bloggers of different ages and identities.

<https://anautismobserver.wordpress.com/>

Learn From Autistic People Blog:
<https://www.learnfromautistics.com/blog/>

Autism Advocacy Organizations

Autistic Self-Advocacy Network (ASAN)

<http://autisticadvocacy.org/>

ASAN is a non-profit organization run for autistic people by autistic people. The organization's motto is "Nothing about us without us." They aim to provide support services for autistic individuals while educating both the autistic and neurotypical public in an effort to improve society's perception of autism.

Autism Network International

<http://www.autismnetworkinternational.org/>

ANI is another organization run for and by autistic people. ANI formed from the need for autistic people to connect with other autistics. They emphasize an anti-cure perspective on autism and currently sponsor "Autreat," an annual retreat and conference for autistic people.

The Autism Acceptance Project (TAAP)

<http://www.taaproject.com/>

The Autism Acceptance Project (TAAP) website states the TAAP is "dedicated to promoting acceptance of and accommodations for autistic people in society...and will bring forth a different and positive view about autism to the public in order to foster understanding and acceptance, and to empower parents and autistic people." The site has links to several blogs by autistic people, parents, and medical professionals, and a variety of resources related to literature that supports autistic rights.

TASH

<http://tash.org/>

TASH is an organization dedicated to disability advocacy. It encourages research, professional development, policy, advocacy, and information distribution to promote the advancement of marginalized communities. TASH organizes conferences and training events to serve this purpose.

Ollibean

<http://ollibean.com/>

Ollibean has a wealth of information and resources for parents learning to advocate for their disabled children. The site features an easy-to-use interface that archives blog posts on a variety of topics and disabilities. Ollibean also offers a community forum of parents, self-advocates, and professionals who support neurodiversity, respect disabled voices, and do not think your disabled child needs to be "fixed" or "cured" in order for him or her to live as a complete human being.

Autism National Committee (AUTCOM)

<http://www.autcom.org/index.html>

AUTCOM is an organization devoted to social justice for all autistic individuals. They provide resources for autistics and autism advocates to establish a voice in the national landscape of autism, including newsletters, articles, information on autism policy and legislation, conferences, trainings, and other publications.

National Disability Rights Network

<http://www.ndrn.org/index.php>

The National Disability Rights Network advocates for individuals of all disabilities, protecting their civil rights and helping promote training and advocacy for other disability rights organizations. Their website features legal information related to a variety of disability rights issues and offers free webinars on a range of disability advocacy topics.

Autism Advocacy Organizations

Self-Advocates Becoming Empowered

<http://www.sabeusa.org/>

Self-Advocates Becoming Empowered is an organization devoted to providing self-advocacy groups with the resources necessary to achieve their mission. Their website has free webinars, blogs, videos, and other training materials of interest to different self-advocacy groups.

Autism Acceptance Month

<http://www.autismacceptancemonth.com/resources/parent/>

This website from the Autistic Self Advocacy Network articulates the difference between autism awareness and acceptance. It encourages people to promote autism acceptance with action and offers specific resources catered to autistic self-advocates, parents, educators, and employers.

Additional Reading

Books

Loud Hands: Autistic People, Speaking—This anthology is published by the Autistic Self Advocacy Network and written entirely by autistic people. This book will break the damaging stereotypes upheld by many neurotypicals and help parents better understand their autistic children.

No Pity: People with Disabilities Forging a New Civil Rights Movement by Joseph P. Shapiro— This book covers a history of disability including social paradigms and public policy. It challenges readers to notice how society treats disability and promote a more accepting culture of equal and interdependent human beings.

Learn to Listen

Autistics have spoken on both sides of the self-advocacy issue. Some argue that autism is good and any attempt to prevent or "cure" it is irresponsible and immoral. Other autistics assert that there are real difficulties to living as autistic and that they would readily accept an opportunity to change themselves. Many others lie somewhere in between. Whatever camp you and your child sit in doesn't deny the fact that learning how to advocate for your child's needs is essential to helping him live an independent and productive life. Teaching and modeling how to live a positive, meaningful autistic life will help you and your child embrace what you can't control and truly appreciate your child's identity.



"If we are to achieve a richer culture, rich in contrasting values, we must recognize the whole gamut of human potentialities, and so weave a less arbitrary social fabric, one in which each human gift will find a fitting place."
-Margaret Mead

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