

A Guide on Self-Advocacy

Contributed by Erik Gallery, Navigator Manager and Katie Oswald, Adult Autism Advocate

In recognizing April as Autism Acceptance & Pride Month, we at the Autism Alliance of Michigan want to acknowledge the diverse needs that Autistic persons and their families experience. For families of children with Autism, being able to navigate necessary resources and addressing the barriers that come with them can be of the utmost importance as a parent. For Autistic adults, being able to find further community and independence options, while maintaining their sense of selves is often integral. The common quality that is necessary in meeting those needs is the ability to advocate for one's self. We hope this guide on the varied skills of advocacy will aid persons in feeling empowered to find and secure the rights of themselves, and those they care for.

Being Your Own Advocate

Advocating for yourself is an important step for having your needs met. Only you know what you need and want. You may have trusted friends, family members, and helping professionals who advise you, but being your own advocate means making your own decisions about your life. Sometimes others advocate for you. They are trying to help, but they don't know what you want and need, so they can't get those things for you. At best, they are advocating for their interpretation of what you told them you need, which may not be exactly what you need. At worst, they will advocate for what they think you need or what they think you should want. Only you know what is best for you and that is why it is important to be able to advocate for yourself.

It is essential to your health and well-being that you have a clear understanding of the things that are important to you. Sometimes we get messages from society or our loved ones that we are supposed to do things a certain way. For example, some people think you have to go to college after high school, but maybe you would rather wait or go to a trade school instead. Others may think you shouldn't get married and have children, but you may want that for your life. It is up to

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you to figure out what is right for you and to advocate for your rights.

For parents, these same items apply to the needs of your children. As the primary caregiver, you have the widest knowledge on what is best for your child, and you see firsthand how specific choices affect them. Hearing the advice of professionals is important, but ensure your voice is also heard. Sometimes you have to be the voice for your child.

Being a self-advocate means:

- You are able to tell people about your thoughts and feelings. This can be verbally, in writing, sign language, using an AAC device, or another method you use to communicate.
- You are able to ask for what you need and want.
- You know your rights and you speak up for your rights.
- You are able to make decisions that affect your life.
- You are able to take responsibility for the choices you make. This means not blaming others for any negative outcomes of your choices.
- Being a self-advocate is a lifelong learning process. That means there is always more to learn, and we can always work toward being a better self-advocate. Much of what we learn about self-advocacy comes from our lived experience. The more you advocate for yourself, the more you will learn about being a good self-advocate.

Foundations of Self-Advocacy

Self-confidence/belief in self

Every one of us is a unique and valuable individual and we each have the right to advocate for ourselves. No one person's needs are more or less important than anyone else's needs. That means you are worthy of the time and effort spent advocating for yourself. Sometimes it is difficult to remember this. We all have moments where we feel confident and moments where we don't. In those moments where you are not feeling confident, remember that you are just as important as anyone else and you have the ability to speak up for yourself.

Self-knowledge

Knowing and understanding your own needs and wants is also crucial for good self-advocacy. If you don't know what you need and want, how can you advocate for it? We all change over time, so learning about yourself is a lifelong process. Here are some questions that can help you understand yourself better. Make sure you understand these things well enough to clearly communicate them to others.

- What are my values?
- What matters to me most and why?
- What are my particular needs?
- What are my goals?

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- What does success look like to me?
- What do I need to accomplish my goals or fulfill my responsibilities?
- What do I need to feel respected and to maintain my emotional, physical, and financial well-being?
- What are my strengths, limitations, and areas for potential growth?

Again, for parents, these same items apply to your children. If they are unable to communicate for themselves, think about how these items would affect them...does this knowledge reflect the goals you pursue?

Strategizing

Part of advocating for yourself is strategizing your actions in the pursuit of finding a solution. An unmet need is a problem that needs solving and as a self-advocate, it is up to you to find that solution. Here are some questions to ask yourself in this process:

- What is the issue?
- What is the negative impact on you and others?
- What is the desired resolution?
- How can it be a win not only for yourself but for others involved?
- What is your best alternative?
- What are your non-negotiables? Non-negotiables are things you are not willing to compromise on.

Knowing the answer to these questions before you begin the journey of advocacy can aid in directing your overall actions. Seeking resources can often lead one down alternate pathways...prioritizing your needs with answers to these base questions can act as a continuous guide as you move forward.

Skills for Good Self-Advocacy

Know and understand your rights

If you don't know what your legal and human rights are, people may tell you that you don't have a right to have your needs met when you actually do. Understanding your rights is an important first step to self-advocacy.

Here are some resources to help you learn your rights:

- USA.gov: <https://www.usa.gov/disability-rights>
- Disability Rights Michigan: <https://www.drmich.org/>
- U.S. Department of State: <https://www.state.gov/promoting-the-rights-of-persons-with-disabilities/>
- American Civil Liberties Union (ACLU): <https://www.aclu.org/know-your-rights/disability-rights>
- United Nations: <https://www.un.org/en/about-us/universal-declaration-of-human-rights>

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Ask questions when necessary

If we don't ask questions when we need clarification, we will not have what we need to have our needs met. It's important that we have all the knowledge, information, and resources we need, and that often requires asking questions. It may require doing research to find out the right person to ask and either sending an email or making a phone call to talk to that person. You may have to ask the same question multiple times to the same person or different people in order to get proper clarification.

Ask for help and guidance from trusted friends, family, and/or professionals

Being independent doesn't mean doing everything without support. It helps to have a support network. Ensure you are taking advice and guidance from trusted individuals, this can include family, peers, and trusted professional providers. Your support people can help by sharing ideas and resources, providing feedback on your plans, or both. Going back to our foundations of self advocacy...it is your choice to either take advice or not take advice. You are responsible for making your own decisions and accepting the outcomes they may bring. This remains true for parents that act on behalf of their children's needs.

Remember to show gratitude

This is a simple effort, but can sometimes go overlooked in the stressors that advocacy brings. It is important to recognize the efforts of those in your support team. Even when the desired outcome isn't met, you'll want to maintain the relationships you create. Oftentimes, the resources we're seeking aren't available, but your support team may be able to aid you in other needs, or at a later time as more options develop.

Don't limit your research to one source

There are several sources of information. You can find information from multiple sources on the internet, from government agencies, and from nonprofit organizations. Be aware of all the resources available to you, how to use them, and who to contact for help with each item.

Express yourself clearly and concisely

When you are communicating, no matter your method of communication, be sure you are clear. Clear communication requires you to stick to the topic without going into unnecessary detail. Be concise and don't say more than you need to communicate exactly what you need. If you need help learning how to communicate your needs more concisely, ask someone from your support network for help.

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Keep a file of all important written communications and documents

Be sure to archive email interactions so you can refer to them later. Sometimes people tell us one thing and then don't remember saying it. It is important to have a record of interactions so you can go back and reference it later if necessary. Also, keep a record of important documents and forms that have information about you and your needs. Anything you sign should be kept for your records.

Learn everything you can about your disability

Since it is your responsibility to communicate clearly about your disability and your needs, it is important to be knowledgeable about your disability, both generally and more specifically about how it impacts you. Know your strengths and limitations and be able to describe them to others. You should know, or at least have an idea, of what accommodations you may need.

Key Steps to Follow for Self-Advocacy

1. Believe in yourself and your ability to get your needs met.
2. Decide what you want. Remember that you know your needs, or that of your child's.
3. Prioritize your needs so you can focus on one at a time.
4. Research any laws and understand your rights regarding the unmet need.
5. Research how to get that need met.
6. Consult your support network to see if they have feedback or input.
7. Based on your research, create a plan for how you will have that need met.
8. Ask one or more people from your support network to review your plan.
9. Take action on your plan.

Repeat these steps as needed. You may need to go back and do more research on the same topic from time to time. Needs and resources change over time and information becomes outdated. It's important to keep up to date on resources and information regarding your needs.

AAoM MiNavigator Program

For both Autistic persons and families, sometimes additional guidance is needed beyond one's own determination. The Autism Alliance is prepared to assist individuals in addressing Autism related needs through their MiNavigator Program. The program is served by professional staff that can act as a guide in identifying resources across the state and offering consultation on next steps as persons pursue solutions. Please use the link below to get connected to a Navigator:

[Contact MiNavigator](#)

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Article Sources:

- <https://uindy.edu/ssd/self-advocacy-principles>
- https://disabilityrightsflorida.org/disability-topics/disability_topic_info/10_steps_to_effective_self_advocacy
- <https://www.lupus.org/resources/what-is-self-advocacy>
- <https://www.wellnessrecoveryactionplan.com/ten-steps-to-being-an-effective-self-advocate/>
- <https://www.betterup.com/blog/self-advocacy>
- <https://www.colorado.edu/today/2020/09/25/how-advocate-yourself>

Additional Self-Advocacy Resources:

- AAoM Resource Directory: <https://autismallianceofmichigan.org/resources/>
- AAoM Community Calendar: <https://autismallianceofmichigan.org/events/>
- Autistic Self Advocacy Network: <https://autisticadvocacy.org/>
- Self Advocacy Research and Technical Assistance Center: <https://www.selfadvocacyinfo.org/>
- Neuroclastic.com: <https://neuroclastic.com/?s=advocacy>
- Thinking Person's Guide to Autism: <https://thinkingautismguide.com/?s=advocacy&id=2839>
- Book: The Autism and Neurodiversity Self Advocacy Handbook: <https://www.amazon.com/Autism-Neurodiversity-Self-Advocacy-Handbook/dp/1787755754>
- Good advice from an autistic person: <https://themighty.com/topic/autism-spectrum-disorder/autism-diagnosis-empowering/>
- Self advocacy in healthcare setting: <https://autismandhealth.org/>
- Advocacy tips from Disability Rights Michigan: <https://www.drmmich.org/resources/advocacy-tips/>



MiPAAC
MICHIGAN PARENT, ADVOCATE
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We want to hear from you!

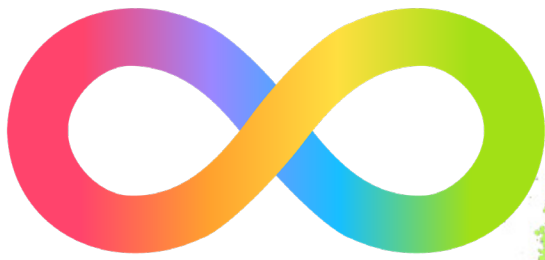
We want to hear from you!

Please take the time to share your experience with special education services and supports for yourself and/or your child(ren).

Your input will inform collective advocacy efforts to help make improvements to access and opportunities for students with disabilities.

Click Here to Start the Survey!





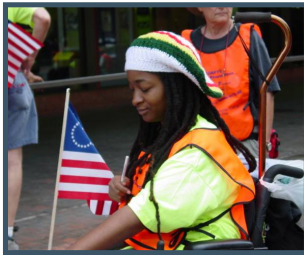
Autism Acceptance Month

Contributed by AAoM's Diversity, Equity and Inclusion Committee



Sue Ann Pien

An actress on the Netflix show *As We See It*, she was kicked out of her first acting school, Sue Ann follows the footsteps of many derelict actors on the autism spectrum by finding humor in offbeat characters.



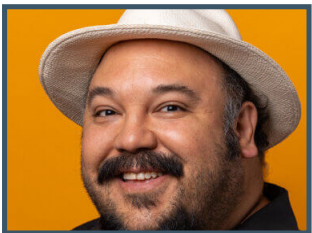
Anita Cameron

A prolific disability rights activist, author, and public speaker, she has campaigned for disability rights since the late 1980's. She also advocates for LGBT+, Black, and Indigenous rights, and for better treatment of people whose identities intersect those categories.



Dr. Vernon Smith

A Nobel Prize winning economy professor at Chapman University, his work in the field practically founded the philosophy of experimental economics. He credits his autism for his success, citing the ability to look at things from a different angle.



Jorge Gutiérrez

An Academy Award nominated director for children's media such as *Book of Life* and the Netflix show *Maya and the Three* and a father of an autistic son, Jorge was diagnosed with Autism at 40 years old. He credits his autism with his drive to bring his home Mexican culture to the world stage of entertainment, no matter the barriers.



Greta Thunberg

Possibly the most famous environmental activist in the modern day, her work in slowing the impact of climate change and in youth activism has had world leaders heeding every word. She has credited her autism as her driving force.



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AAOMWALK.COM!



AutismAlliance
of Michigan

AUTISM HERO WALK GRAND RAPIDS

SUNDAY, JUNE 25TH, 2023

MILLENNIUM PARK : WALKER, MI



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MICHIGAN SHINES FOR AUTISM GALA

FIGHTING FOR CIVIL RIGHTS
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Casino Hotel
Detroit, MI

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FOR MORE INFORMATION VISIT AAOMI.ORG OR CALL 877.463.2266

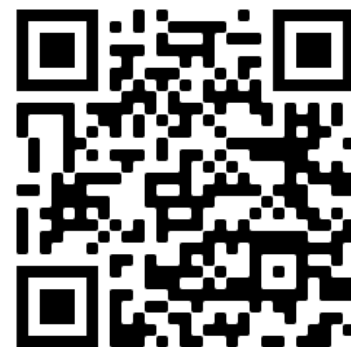


Upcoming Community Events



Date	Event	Location
April 14 - 16	Kiwanis Home and Garden Show	Escanaba
April 15	FALCONERS - Potter Park Zoo	Lansing Charter Township
April 15	NAMI Michigan Honors Black Tie Gala	Dearborn
April 20	Spring Vibes Social	Southfield
April 22	Seidman Park - Hiking Group	Ada
April 24	Drawing Workshop at Hearts for the Arts Studio - Teen and Young Adult Social Group	Grand Rapids
April 25	Sensory Friendly Spartan Concert	East Lansing
May 1	22nd Annual START Conference	East Lansing
May 13	“Full Spectrum Players” Theater Group Performance	Grand Rapids
May 23	Walk for Autism	Comstock Park

Looking for more to do?
Scan the QR Code for
more events!





POWERED BY AUTISM ALLIANCE OF MICHIGAN

Upbound Staffing, a fully integrated program within the Autism Alliance of Michigan, leads and supports disability-employment initiatives throughout the State of Michigan.

Contact Upbound Staffing:

Website: <https://upboundstaffing.com/>

Email: upbound@aaomi.org

Phone: [1-\(248\) 508-8693](tel:1-(248)508-8693)



MiPAAC

MICHIGAN PARENT, ADVOCATE
& ATTORNEY COALITION

Powered by  Autism Alliance
of Michigan

Michigan Parent, Advocate & Attorney Coalition (MiPAAC) is a newly formed statewide group focused on student centered advocacy.

Contact MiPAAC:

[MiPAAC membership Form](#)

<https://mipaac.org/>



MiNavigator

The MiNavigator team is a group of professionals ready to serve and connect those touched by autism with the most up to date services and resources available in our state.

Contact MiNavigator:

Website: <https://aaomi.org/contact-minavigator/>

Email: navigator@aaomi.org

Phone: [877-463-2266](tel:877-463-2266)

Navigators are available Monday through Friday,
from 9 am to 5pm

