

CASD CHAT E-Newsletter

Empowering Autistic Youth to be Self-Advocates

What is self-advocacy? Self-advocacy is a topic that is increasingly discussed in connection with autism. Often, we hear in the media about adults who are autistic advocates, such as those in organizations like the *Autistic Self-Advocacy Network* or the *Autism Women and Non-binary Network*. These individuals have made a career out of advocating for the rights of autistic and other disabled people. They are increasingly powerful and well-respected in political spaces, and they have played important roles on policy initiatives as large and wide-reaching as the Affordable Care Act or student loan debt forgiveness. Although often labeled “self-advocates,” a more accurate term for these influential individuals is “political advocates” or “community activists”, who are making change not just for themselves, but for the disability community more broadly.

While relatively few children will go onto become advocates in this way, every child and teen should be empowered to be a **self-advocate**. At its core, self-advocacy is the ability to speak up for oneself and tell others what you need in order to be happy and successful. Self-advocacy is a critical skill that begins developing in childhood and continues through adulthood. Research has shown that for people with disabilities in particular, quality of life (how happy and fulfilled by their life a person is) is strongly related to self-advocacy. Self-advocacy is often more strongly related to quality of life than even more concrete factors like a person’s education, or employment, or living situation. Simply put, people who know what they need and want, and are able to ask for it, feel happier!

How can autistic youth develop self-advocacy skills? Self-advocacy is a skill that develops over time, so we can begin supporting and teaching these skills at any age.

For young children:

- Self-advocacy often begins with practicing identifying their feelings and sharing those with others, like being able to tell others when they are upset, or don't like something, or need a break. Adults can support this by modeling talk about their own feelings and making sure to listen and validate children's feelings. Even if we cannot "fix" the situation that's making them upset, we can let them know that we understand and try to help them feel better or at least identify options in a difficult situation.
- This also means that we need to be cautious about forcing children to share or take turns. Adults can also help children to learn appropriate ways of advocating like saying, "I'm not done with that yet" or "This toy is really special to me" or by offering to make a trade.
- It's also important to model appropriate personal space by asking before hugging or touching the child and encouraging adults outside the family to use high fives or fist bumps, rather than assuming it's okay to hug.
- For children who are not communicating verbally, teaching ASL signs or programming in AAC supports that allow them to communicate things like "I don't like that" or "Stop please" or "I need a break" can support their self-advocacy development.

For older children and pre-teens:

- We can build self-advocacy skills by helping youth begin learning the triggers or situations that are difficult for them and the coping and conflict-resolution strategies they can use. At this age, youth can start to recognize things like how noisy environments, specific academic tasks, or changes in routine affect them. They can also learn to identify which coping strategies (e.g., taking deep breaths versus reading a book) help them and let others know which they prefer.
- This is also a good age to begin working on skills for resolving conflicts with both peers and adults in respectful, appropriate ways. Youth can learn to express that they have a different opinion, or that they would like to do something in a slightly different way. Learning how to make a compromise is a great strategy for self-advocacy. The book *Solving Executive Function Challenges* by Lauren Kenworthy is a great resource for learning about how to do this.
- You can continue building skills for advocating around their bodies and personal space by helping youth to tell others what kinds of touch they do and do not like. Also consider allowing youth to communicate when they can make eye contact, versus when they need to be able to avoid eye contact to regulate and communicate at their best.
- For youth who have more limited verbal communication skills, they can learn to use simpler phrases (either verbally or through AAC) to express these ideas, such as "5 more minutes" or "I do it this way" or "It's too loud."

As teens prepare for young adulthood

- It is a critical time to build skills for knowing themselves and advocating for how they learn best. Adults can help youth continue to identify and express what situations are most triggering or stressful for them, as well as the accommodations and supports that allow them to succeed.
- This is also a great time to "conduct experiments" in which teens can test out different strategies to support their own learning and independence, rather than relying on the adults around them. At this age, it's important for adults to step back and allow teens to try out strategies that may be

different from their own approaches to let them learn for themselves, and then share their “findings” with others. Teens should also learn about any formal supports that they may be getting through a 504 Plan or Individualized Education Program (IEP) and participate in those meetings to provide input on their own goals and accommodations.

- Adolescents also need to have clear, direct conversations about how to ask for and express consent when it comes to personal space, peer and adult relationships, and romantic relationships. Teens should be encouraged to communicate how others’ actions make them feel and learn how to set their own boundaries.
- For adolescents who do not usually communicate verbally, it is critical to maximize their opportunities to communicate for themselves. It is common for people like teachers or therapists to talk to family members about the teen, rather than talking to the teen directly, or to talk to the teen as though they were much younger. These patterns often continue into adulthood. It is important to empower these teens to express their thoughts and wishes directly to others and to be sure their voices are heard.

Becoming an effective self-advocate is a lifelong journey, and we can all continue to be better at advocating for ourselves. By listening to your child’s thoughts and feelings, modeling respectful communication, and encouraging youth to speak up for themselves, families can prepare their children to advocate for themselves throughout their lives.

This article was developed by Allison Ratto, Ph.D., CASD Clinical Psychologist, Ashley Muskett, Ph.D., CASD Clinical Psychologist, and with the assistance of Andrea Lopez, B.S., CASD research assistant. Scroll down for a list of resources (including tools you can download), announcements of community programs, and research opportunities. Our goal is to help families and providers so please use the QR code at the end of the CHAT to give us feedback.

Profiles Celebrating Neurodiversity



Tiffany Hammond

Tiffany Hammond (she/her) is an Autistic mother of two autistic sons, advocate, and storyteller who uses her personal experiences with Autism and parenting two Autistic boys to guide others on their journey. Tiffany has a Masters in Developmental Psychology and spends her time teaching, coaching, and mentoring others in Disability Justice issues. Her activism is rooted in challenging the current perception of Autism as a lifelong burden, cultivating a community that explores the concept of Intersectionality and inspiring thought leaders through storytelling, education, and critical discourse. She recently published a book (coming out in May 9th) called "A Day With No Words" that's a children's book told through the perspective of one of her sons, who communicates through Augmentative and Alternative Communication (AAC).

[Click here to learn more about her book](#)

[Click here to visit her Instagram](#)

2022 Calendar of Events

Rock Autism

Where: Hard Rock Café in Washington, D.C.

When: March 3, 2023

Rock Autism is a non-profit organization that strives to “support individuals on the autism spectrum to develop a craft in music, film and the multimedia arts

that lead to employment in their given field of interest.” Rock Autism is hosting a national tour this year, which includes a concert at the **Hard Rock Café in Washington, D.C. on March 3, 2023.**

[Click here to purchase tickets](#)

Additionally, Rock Autism is offering volunteer opportunities for students on the spectrum aged 14-26, to shoot pictures and videos at the event. For more information on volunteer opportunities, please feel free to contact Alea Conte, directly at alea@rockautism.org.

[Click here to learn more about Rock Autism](#)

Free Parent Support Group

Where: Virtual

When: Every Monday at 1 PM EST

Dr. Dan Shapiro, friend of CASD, will be offering a free parent support group, every Monday at 1 PM EST. To register, [click here](#).

Dr. Shapiro is offering new courses for parents of different age groups on a wide range of topics. Choose the topics that interest you. Real-life challenges. Real-life solutions.. To learn more about these courses, visit [parent-child excursions](#): More information on various programs can be found on his website: <http://www.parentchildjourney.com/>

Participate in Research

Unstuck & On Target High School Project

There is an exciting new research project from Children’s National Hospital and we are looking to partner with local high schools in the DC Metro area!

In partnership with educators, autistic youth, and their families, autism experts from Children’s National Hospital have developed an upward extension of the school-based *Unstuck and On Target!* curriculum for **diploma-track, autistic high**

school students needing executive function and socio-emotional support. This research-based curriculum is designed to be taught at school and targets transition-readiness skills such as self-advocacy, flexible problem-solving, time management, and independent goal-setting and planning skills.

Unstuck & On Target: High School Curriculum

Understanding Your Thinking Style & Getting What You Need

Flexible Thinking, Self-Advocacy, Neurodiversity, Managing Mismatches

Tools to Keep You On Target

Time Management, Handling Stress, Motivation, Reminder Systems

Tools for Working With Others

Relationship Builders, How & When to Compromise

Planning Your Goal and Putting Your Plan Into Action

SMART Goal Setting, Seeing the Big Picture & Important Details, Recognizing Planning Dangers, Making & Trying Out Your Plan A/B/C

We have received funding from the National Institutes of Mental Health to evaluate the (free) curriculum on a larger scale, and **we are looking for schools to partner with**. Once we receive approval from the school district, we will provide participating schools with free training, materials, and ongoing support for school staff to teach *Unstuck* at local schools.

If you are a teacher or parent and are interested in hearing more about how to bring *Unstuck* to your high school or school district, please contact Julianna McKenna at jmmckenna@childrensnational.org.

Praise from Parents & Teens



RDoC Executive Function Research Project

Georgetown University Developmental Cognitive Neuroscience Laboratory and Children's National Hospital are studying executive function skills like attention, memory, and learning using magnetic resonance imaging (MRI). Using MRI technology, we expect to pinpoint the parts of the brain that are responsible for these cognitive functions and hope to determine the potential of using MRI as a tool to help clinicians personalize treatment. We are recruiting 8-13 year olds with a clinical psychological diagnosis (of any kind), no genetic conditions, no metal in their bodies, and no neurological conditions.

If you are interested, please contact Laura Campos:

- Phone: 301-765-5478
- Email: lcampos@cnmc.org



ASD Research Study

George Washington University and George Mason University are study brain development in autism. As part of the study, participants play child-friendly computer games while we track their gaze and brain function. Families can early up to \$90 for participating.

We are recruiting 5-17 year olds with an autism diagnosis.

If you are interested in participating, please contact Chelsea Armour:



- Email: aarmour@childrensnational.org or andilab@email.gwu.edu

Unstuck & On Target Resources



A resource for **TEACHERS!**

- Free, asynchronous, online educator training
- First 600 to finish get 3.5 free CE credits!

Unstuck Elementary is a Tier 2 executive functioning curriculum

- Planning
- Transitioning
- Following directions

Click here

"One student had three meltdowns per day, and unstuck reduced her outbursts to two a quarter."



A resource for **PARENTS!**

Free, online supports for preventing overload, compromising and staying motivated

Created by parents, educators, and experts

- 15 3-5 min videos
- 5 also in Spanish
- Tip sheets

Click here

"The videos made me feel less alone...and hopeful that there are more things I can try to help [my child]."



¡Feliz Mes de la Herencia Hispana!

Explora nuestros recursos en Español:

- Videos en Español
- Manual para padres en Español

Haga clic aquí

A continuación: Todos los videos traducidos al Español Grabación de seminarios web en Español para implementadores

Unstuck Elementary es un plan de estudios de la función ejecutiva de Tier 2 para estudiantes neurodivergentes

"Un estudiante tuvo tres crisis por día y Unstuck redujo sus arrebatos a dos por trimestre."



Un recurso para PADRES

- Apoyos gratuitos en línea para padres de niños con dificultades para manejar las emociones, concentrarse, hacer planes y más

Creado por padres, educadores y expertos.

- 5 videos de 3-5 minutos en español
- Hojas de consejos

Haga clic aquí

"Los videos me hicieron sentir menos solo... y con la esperanza de que hay más cosas que puedo intentar para ayudar [a mi hijo]."

The *Unstuck* author team has created short videos to help parents of children with executive functioning difficulties. Please click the playlists below to view the videos in both

English and Spanish! **We have added new videos to address feedback from parents. Please click on our playlist to view our new 3-part video series on "troubleshooting."**

The videos made me feel less alone.
--Parent

The strategies were very well explained.
--Parent

New Free Videos
UNSTUCK
AND ON TARGET

Playlist of all videos

Recursos para padres



Click here for the video

The Talk—Black, Autistic, and Male: One Family's Experience

We would like to share an interview with a family of a college-bound autistic young adult and an accompanying reflection by Tawara Goode, Director of the National Center for Cultural Competence and Director of the Georgetown University Center for Excellence in Developmental Disabilities.

Additional Resources

Arc Maryland, "Together We're Better"

The Arc Maryland, with its statewide partners, provides a school inclusion program called "["Together We're Better" \(TWB\)](#)". The objective of the program is to raise awareness of the value and importance of inclusion of students with disabilities. The program involves a 4-way partnership with the Maryland State Department of Education, the Maryland Developmental Disabilities Council, the Maryland Department of Disabilities, and The Arc Maryland. [Visit the website here](#) to see the different components to the program, broken up for elementary, middle, & high school students.

DC Autism Collaborative

The [DC Autism Collaborative](#) (DC-AC) has developed several resources for parents of young children and professionals (including health providers, early childhood educators, and community leaders) on topics related to autism spectrum disorder

(ASD). All materials have been, or are in the processes of being, translated into both Spanish and Amharic. These resources can be downloaded as PDFs, though we encourage you to [visit the website here](#) as we plan to update these regularly.

Pathfinders for Autism

Pathfinders provides a list of programs for all ages including video group for spouses/partners of adults with Asperger's; Transitioning services and Job skills; Baby and Family Navigator programs, and new this month, Autism from the Autistic Perspective and free Pediatric Occupational Therapy Screening and more!

<https://pathfindersforautism.org/calendar/>

20+ free resources available to view anytime, anywhere!

Enjoy these [information-packed free webinars](#) on your own or make them a powerful group learning event with your colleagues, friends, and family members. Topics include:

- Working/learning in groups
- Face-to-face communication
- Social anxiety
- Executive functions
- Children's stress
- Self-regulation
- Individual webinars on 10 core Social Thinking Vocabulary

Hosted by Social Thinking

Supporting Mental Well-being

Yetta Myrick, Executive Director/President of [DC Autism Parents \(DCAP\)](#) and CDC's Act Early Ambassador to the District of Columbia has multiple resources to share with families to support mental well-being.

[Tips to Help Parents Keep Calm Every Day](#)

Additional Resources

Advocacy Resources

[Autistic Self Advocacy Network-Navigating College: A Handbook on Self Advocacy](#)

Resources on Anti-Racism

[Spectrum Support's Social Stories on Racism](#)

[ASAN's What is Police Violence?: A Plain Language Booklet](#)

[@TheMorganCruise Worksheets for Black Children](#)

COVID-19 Safety Resources

COVID-19 National and Local Government Resources

[Centers for Disease Control and Prevention](#)

[World Health Organization](#)

[DC Department of Health](#)

[Maryland Department of Health](#)

[Virginia Department of Health](#)

[U.S Department of Education's Individuals with Disabilities Education Act \(IDEA\) Part C
Dispute Resolution Procedures](#)

[U.S Department of Education's Individuals with Disabilities Education Act \(IDEA\) Part B
Dispute Resolution Procedures](#)

Visit Children's National Hospital COVID-19 Resources



If you have feedback or suggestions, please scan the QR code and complete the survey!
Thank you!