



CASD CHAT E-Newsletter

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Talking to Your Child About Their Autism Diagnosis

It's one of the most common questions we're asked when we talk with parents of a newly diagnosed child- Do I tell my child that they're autistic? The answer- almost always- is yes. Now, in therapy we talk a lot about how 'always' isn't a helpful word. The reason is that there really is no such thing as "always." There may be a unique situation where the generally recommended advice doesn't apply and ultimately you decide what is right for your family. However, the goal of this article is to help you understand why we at Children's almost always recommend talking to your child about their autism diagnosis, as well as some ideas about how to go about it.

Reason One: Kids are smart. Most of the time, kids have a sense of when something about them is different than other kids. And kids are in a development phase where they are trying to understand themselves, their world, and how the two go together. Whether we intended it or not, kids are always trying to make sense of the world and their place in it, and telling themselves stories about why things are the way they are. Unfortunately, what we know from research on the development of self-esteem in Autistic young people is that, without an explanation for why some things are hard for them (that are easy for their peers), the stories that Autistic people tell themselves aren't very happy ones. The things kids tell themselves may sound like, "I'm not smart," "I don't belong in this family," or "I'll never be good at anything." We want to give them language and knowledge about autism so that the stories they tell themselves can instead sound like, "I need help to do my best when switching between tasks, but it's getting easier for me," "My brain works differently, but the people who love me, love that about me," and "Autism makes some things hard, but it means I'm really good at some things too."

Reason Two: It gives them access to new communities, friendships, and sources of joy. Research suggests that one of the things that is most protective for the mental health of Autistic children is engaging them in their special interests and connecting them with others who share their passions. Connecting them to groups of other Autistic children gives them a chance to connect with others who experience the world through a lens that may be more similar to their own. This can lead to greater inclusion, more sense of belonging, and higher self-esteem.

You may be thinking- that's great Ashley but you talk about stuff like this all the time, so you know exactly what to say- how am I supposed to approach this conversation as a parent? First of all, to reassure you, these conversations are hard for professionals too! This is because every child is so different, has their own set of needs, and has a different level of information they are ready to receive. When I'm training new (and often very nervous!) therapists, I tell them that there are very few mistakes they could make as a therapist that we won't be able to work together to put right. The same is true of this conversation- parents make mistakes, and kids are resilient. Even if the conversation doesn't go as you'd hoped, there is usually something positive to be gained. That said, we do have some tips to help you feel more confident talking to your autistic child about autism:

- 1. It's not really a conversation so much as it is conversation(s).** Autism is a lifelong identity and the way you talk to your child about autism at 5 years old is different from how you'll talk about it when they're 15, and different again from how you'll talk about it when they're 25. There's no need to put pressure on one single conversation, even if it is the first time your child is learning that they are autistic. You're just starting a conversation that you'll keep having for the rest of your child's life and there will be plenty of opportunities for you to keep learning and growing together.
- 2. Emphasize strengths.** Autism is a part of a child's identity that comes with numerous strengths. And some of these strengths are impossible to separate from their autistic identity. Some of examples of common Autistic strengths are below. Often when I talk with kids about autism, I have them look at a picture like this and pick out some things that they feel may be strengths for them.
- 3. But don't be afraid to validate difficulties.** We talk a lot at Children's about providing care and services for children that are neurodiversity-affirming or that acknowledge autism as an essential part of a person's identity. But it doesn't mean we can't acknowledge the things related to autism that are hard. Many kids with autism struggle to communicate, to manage their feelings and behaviors, and to feel accepted in a world that

is much better suited to neurotypical people because they generally have their own challenges recognizing the perspective of neurodivergent individuals and how to support neurodivergent individuals and how to support them. You should absolutely acknowledge and empathize with the things that are hard and explain to your child that there's a reason these things are hard for them, and it has nothing to do with not being smart, or kind, or good. It's because they're autistic and most other people aren't - and that can be really hard!



Sometimes it helps to have a solid example, so below is an example of how this conversation might look with a verbally fluent, elementary-aged child:

Sample Script:

Dad: “Emma, you know how we went to the doctor’s office, and you did all those puzzles and talked to the doctor about feelings and friends?”

Emma: “No.”

Dad: “You got to pick out a toy to take home at the end, remember?”

Emma: “Oh yeah! I put that somewhere. Do you know where I put it?”

Dad: “I want to talk with you about something-“

Emma: “Can you help me find my toy?”

Dad: “Yes. Okay. Let’s make a plan here. First talk, then I can help you look for toy? Sound good?”

Emma: “Okay.”

Dad: “Here- do a quick activity with me. I’m going to fold some papers in half and we’re each going to write some things that are easy for us on one side, and some things that are hard for us on the other side. I can help you if you can’t think of anything.”

[They take a few minutes and complete this activity. Emma’s Dad helps her when she can’t think of something to add and by the end, they each have a list of 3-4 things on both sides of the paper].

Dad: "Wow, look at that. We both have things that are hard for us, and some things that are easy for us. Everyone has things that are hard for them and things that are easy and some of our lists have names. Your list is called autism. You are Autistic and that means that there are some things that are hard for you, and some things you are really good at. Like, you know how you only drink milkshakes with a purple straw? But you see that your little brother doesn't care what color straw he uses?"

Emma: "Uh-huh"

Dad: "Well, a lot of Autistic people like to do exactly the same thing in the same way each time they do it because it feels comfortable and safe."

Emma: "Aiden's not Autistic?"

Dad: "No, Aiden's not Autistic. Most people aren't Autistic- your brain is kind of rare and unique. Sometimes that will be pretty cool, and sometimes that will be hard."

Emma: "It will be hard? Why will it be hard?"

Dad: "Well, like for example with the milkshake- how do you feel when you can't find a purple straw?"

Emma: "NOT good. Because sometimes I really want my milkshake."

Dad: "Exactly- so sometimes I might have to help you figure out how to do things a little differently so you can still have the thing you want."

Emma: "But it will also be cool?"

Dad: "Definitely. You know how you know everything about Pokemon? A lot of the time Autistic people are really good at remembering information about the things they care about."

Emma: "Do you think being Autistic means that soon I'll be able to remember the name of all 1025 Pokemon?"

Dad: "Maybe! But the really important thing I want you to know is that-

Emma: "I already know the original 151."

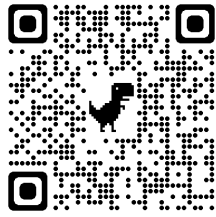
Dad: "That is excellent news! Does everything I'm saying make sense so far?"

Emma: "I think so. Can I go watch Bluey now?"

Dad: "Sure!"

This conversation wasn't perfect! Emma clearly would have rather continued on with her day instead of pausing to have a conversation and her engagement was up and down. Her Dad didn't talk about the social part of autism- which is a pretty big part of the diagnosis! But the point is- this conversation opened a door. There will be plenty of time for conversations about how Emma navigates the social world, self-advocacy, and flexibility but for now, she knows that her Dad wants to help her with the things that are hard for her and sees the

strengths that are part of who she is. If that's all you can communicate before your child runs off to watch Bluey, you're doing just fine.



If you have feedback or suggestions, please scan the QR code or **CLICK HERE** to complete the survey! Thank you!

This article was developed by Ashley Musckett, Ph.D, and with the assistance of Andrea Lopez, B.S., CASD research assistant and Laura Campos, B.A., CASD research assistant.

Neurodiversity Spotlight

Devin O'Connell

Growing up with autism, Devin O'Connell struggled socially, had difficulty making friends, and encountered bullying at a young age. Fortunately, he followed his passion of becoming a race car driver. He began racing go-



karts at the age of nine. The environment at the track proved to be a great place for Devin to socialize with other kids who also loved to talk exclusively about racing and cars. Devin uses what he has learned to empower others and uses his gift of public speaking to talk to schools and other groups about having autism and how he has managed to turn his disability into a different type of ability.

[Devin O'Connell Racing \(devinoconnellracing.com\)](http://devinoconnellracing.com)

2023 Calendar of Events

Special Needs Undergraduate Swim Lessons (SNUGS)

SNUGS at Georgetown University is a student organization offering free, one-on-one swim lessons to children with disabilities in the Washington, D.C. community, but families do not need to live in DC. Some classes still have openings, but will start soon. Additional information is available [here](#).

Interested participants can contact the current SNUGS student president, Makenzie Thomas with questions at mst82@georgetown.edu.

Parent/Child Journey

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/>

Winter 2024 In-Person Event:

- When: Feb 1 - April 4. ten consecutive Thursday nights, 7:30-8:30PM
 - Where: In-person at St. Columba's Episcopal Church Conference room #212 - 4201 Albemarle St, NW Washington, DC 20016
 - With: Dan Shapiro, MD
 - Cost: \$200 (one fee for all ten session and complete video course material)
 - Class Size: maximum 25 participants
-

Ivymount Outreach Resource Fair

Register: Click [HERE](#) to learn more. More information will be provided soon.

Location: Ivymount Campus, 11614 Seven Locks Road, Rockville, MD

Date & Time: Sunday, March 3, 12 pm - 3 pm

Ivymount will be hosting the 11th annual Outreach Resource Fair. Both exhibitors and attendees are welcomed. More information to be provided later in January. Mark your calendars!

Questions? Email outreach@ivymount.org

Ivymount Spring Educational & Therapeutic Programs

Register: Click [HERE](#) to learn more about the educational and therapeutic programs

Ivymount's individual and group programs are designed for Neurodivergent individuals and their families and are provided by our expert teachers and therapists. With defined goals and objectives, Ivymount provides Unstuck & On Target! executive function groups, Applied Unstuck executive function groups, Self-Advocacy Programs, Friendship and Conversation Programs, and Speech Therapy, Occupational Therapy and Tutoring across various ages.

Questions? Email outreach@ivymount.org

Partners in Policymaking

Where: In Person & Virtual Events

When: January 2024 - September 2024

Take your advocacy to new heights through Partners in Policymaking®! Maryland's year-long program prepares adults with intellectual and developmental disabilities (IDD), parents, and family members of children and adults with IDD to be effective advocates at the local, state, and federal levels. Through 12 sessions, Partners in Policymaking® participants will learn about systems change: creating, working towards, and achieving a vision of shared values about people with disabilities. Partners graduates often become lifelong and long-term agents of change in the community. Partners in Policymaking® is free for participants due to the incredible financial support of the Maryland Developmental Disabilities Council, with each spot in the program valued at over \$6,000. Applications for the 2023-24 Partners class are now open! Be sure to apply by October 16th at noon to participate in the upcoming class.

To apply and read more, [click here](#).

DC Peer Programs for Neurodivergent Youth & Adults

[DC Peers](#) is a community organization that offers social meetups, learning workshops, and a welcoming community to neurodiverse groups of teens and adults. Our neurodiverse staff have a lot of personal and lived experience with autism, ADHD, and other neurological differences, and we understand and embrace neurodivergent ways of being in the world. In our groups, folks can be themselves and connect – outside of clinics and therapeutic settings.

Register [here](#) for the following programs:

- Social Meetups
 - middle school, art, games, dungeons and dragons, teens discord and adult meetups
 - Support Groups and Facilitated Discussions
 - Teen and adult neurodiversity, women and non-binary persons support, and parent circle
 - Neurodiversity Workshops
 - Social Strategies Workshops
-

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!

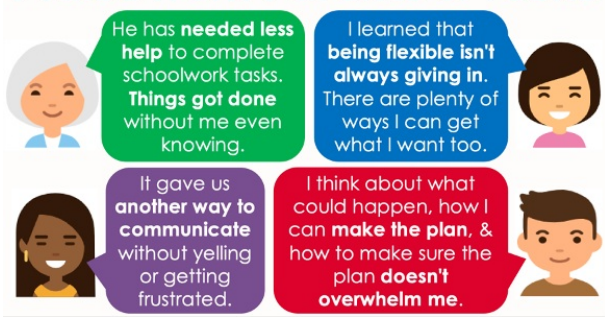
Unstuck & On Target: High School Curriculum
Understanding Your Thinking Style & Getting What You Need
Flexible Thinking, Self-Advocacy, Neurodiversity, Managing Mismatches
Tools to Keep You On Target
Time Management, Handling Stress, Motivation, Reminder Systems
Tools for Working With Others
Relationship 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

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.

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



ASD Research Study

Are you and your child interested in learning about the brain? Is your child 7-17 years old? Are they on the Autism Spectrum? The George Washington University and George Mason University team would like to invite you and your children to play child-friendly computer games while tracking their brain function. The team pays \$20/per hour for participation!

Paid Research Study for Kids 7-17. Earn up to \$120 for participation!

Interested? Contact:



- andilab@gwu.edu

Or click [here](#) to visit the website!

Daily Living Skills Study

The purpose of this research study is to gain insight into what daily living skills are important to you, and what is the best way to write questions about daily living skills for a new questionnaire.



We are recruiting 18-30 year olds with an autism diagnosis.

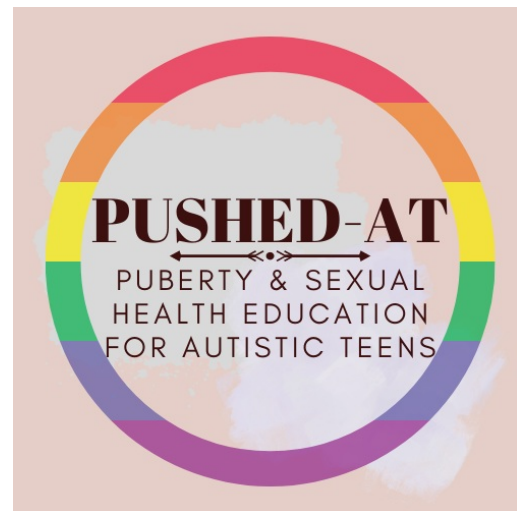
If you are interested in participating, please contact Jamie Kleiner:

- Email: dailylivingskills@chop.edu

PUSHED Study

Are you interested in a puberty and sexual health education program for autistic youth? We are conducting a research study to understand better how autistic youth and their families can learn together about pubertal development and sexual health.

We are inviting families with a child/adolescent diagnosed with autism spectrum disorder or who self-identifies as autistic and who is in the 9th to 12th grades or between 14 and 19 years old.



This is an online study. Families will be asked to complete the online puberty and sexual health toolkit, answer questions about their experience with the toolkit.

Families will be compensated \$100 for their time participating in this study.

Please contact Jenny Phan for more information about the study at (240) 397-8208 or jmphan@childrensnational.org.

ASD Research Study - DSCN Lab

Dr. Elizabeth Redcay at the University of Maryland, College Park and her team are studying behavioral and brain responses in children and adolescents on

the autism spectrum during social interactions. Participation involves virtual visits, in-person visits, and longitudinal virtual follow ups over the course of about two years. Families can earn up to \$100 for their time.



We are recruiting 11-14 year olds with an autism diagnosis.

If you are interested in participating, please contact Kayla Pereira:

- Email: marylandbrainstudy@umd.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



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

Social Thinking Free Resources

For over 25 years [Social Thinking](#) has been a guiding resource for schools, clinics, and families around the world, and they're here for you, too! Their Free Stuff Portal is filled to the brim with teaching ideas and resources to foster the development of students' social competencies. Discover free support strategies to use with your students, clients and children.

[Click here](#) to view Hundreds of Free Resources

Ivymount Outreach Resource Guide

[Ivymount Community Outreach](#) partners with service providers to bring families a helpful one-stop spot for information. The Outreach Resource Guide 2023 is an online tool with information on 70 plus diverse organizations that provide specialized services. The Guide includes provider descriptions and

links that help you easily navigate to meaningful supports.

[Click here](#) to view the Ivymount Outreach Resource Guide

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/>

xMinds

A collaborative partnership of parents, educators, and service providers working together to improve the educational experience and outcomes for autistic students in Pre-K–12 education in Montgomery County, MD. Free resources in English and Spanish!

<https://xminds.org/>

MCTransitions

MCTransitions is a grassroots listserv for adults with disabilities, families and professionals advocating for adults with mild to significant disabilities as they transition from school age entitlements in Maryland to young adulthood and beyond. Purpose is to share information, provide each other support, and work to improve services and outcomes for adults with disabilities in the State of Maryland.

<https://groups.io/g/MCTransitions>

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

[Behavioral Directions LLC's Safety Teaching Protocol](#)

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**](#)

Children's National Hospital, Center for Autism Spectrum Disorders | 15245 Shady Grove Road,
Suite 350, Rockville, MD 20850

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