

## CASD CHAT E-Newsletter

### The Intersection of Autism and Genetic Disorders

In a previous CASD Chat we talked about genetic testing after an autism diagnosis. Now, let's look at the flipside of that- Autism in children who were first diagnosed with a genetic condition. For these children, their autistic traits, the diagnostic process, and intervention can be different from the wider autistic community!



Many genetic diagnoses increase the likelihood that a child will be diagnosed with Autism. For example, we know that children with Fragile X, Down Syndrome, Cornelia de Lange Syndrome, Tuberous Sclerosis Complex, Angelman Syndrome, and Rhett Syndrome are all more likely to be autistic. We also know that having a genetic disorder and an intellectual disability increases the likelihood of Autism even more. Finally, we know that autistic characteristics can look different in children with genetic diagnoses. Some disorders even have a particular “flavor” or presentation of autistic traits!

Because of all this overlap, diagnosing autism in children with genetic disorders and intellectual disability can be tricky, but for many families, an autism diagnosis may be helpful in understanding why their child seems different from others with their genetic diagnosis. While this can be overwhelming for families at times (children with genetic diagnoses often have a lot going on including Autistic traits, and medical complexity) recognizing autistic traits can help guide intervention, including intensive behavior intervention and communicate support needs.

Even with an autism diagnosis, intervention should always be individualized. Families should be aware that research on autism and autism intervention rarely includes individuals with genetic diagnoses! This means that interventions need to be flexibly molded to the needs of the child and the family, with expectations for more incremental progress. Classrooms and programs designed for the wider autistic community may or may not be a great fit.

For families with children with genetic changes, the University of Birmingham has a handout on the process of autism assessment:

- [Click here](#) to view this assessment!

For individual genetic syndrome, advocacy and family groups often have similar resources:

- [National Down Syndrome Society](#)
- [National Fragile X Foundation](#)
- [Tuberous Sclerosis Alliance Complex](#)

For individuals with less common genetic changes, unique gathers family experiences, including information on autistic-traits: [click here](#).

As a last note: there is debate among doctors, parents, and people with genetic conditions about whether or not it is appropriate to diagnose Autism in children with genetic conditions or whether Autistic traits should be considered as just a part of the existing genetic diagnosis. While we've discussed some reasons that an Autism diagnosis may make sense or be helpful for children with genetic conditions (and for many families, an Autism diagnosis may not be the right fit for their child with a genetic condition), this is a complicated topic that we hope to explore more in future CASD chats!



**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 Muskett, Ph.D, and with the assistance of Andrea Lopez, B.S., CASD research assistant and Laura Campos, B.A., CASD research assistant.*

## Neurodiversity Spotlight

### Asa

Below one parent offers their perspective on their journey with their child with Phelan-McDermid syndrome (PMS) and Autism:

*“Asa is an eight-year-old boy with Phelan-McDermid syndrome (PMS), a highly disabling genetic disorder primarily associated with changes to the SHANK3 gene.*

*PMS patients require a multidiscipline treatment team because it causes myriad symptoms, including autism, intellectual disability, developmental delay and regression, sleep disruption, seizures, psychiatric disturbance, hypotonia, lymphedema, and more. There is currently no treatment for it—only symptom management. Most individuals with PMS need*



high levels of support through their lives, though its manifestation can vary significantly from person to person.

*Asa has practically no understanding or use of language. This absence of receptive language greatly limits what Asa can learn. The most basic activities of daily living—such as sitting and allowing a caregiver to put his shoes on—must be taught 1:1, using a hand-over-hand method, in hundreds or thousands of repetitions. Skills that are not practiced daily can disappear very quickly.*

*A few years ago, Asa's anxiety burst into full force. First, Asa began to bite his therapists and caregivers; after a few months, ABA therapy was quite successful in minimizing this behavior. But before too long, Asa began an even more distressing behavior: self-injury. At its worst, Asa was hitting himself hundreds of times a day, leaving marks and bruises. It took nearly a year to discover the right medication to reduce his anxiety.*

*Although Asa's family is grateful for the challenges they are currently being spared, they know the worst is almost certainly yet to come, because that is nearly always how PMS progresses. The silver linings are few and far between. Asa's mother Talya volunteers her time and efforts as vice president at CureSHANK, a nonprofit that is laser focused on accelerating treatments for PMS by helping to bridge the translational research gap between basic SHANK3 science and clinical trials."*

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## 2023 Calendar of Events

### **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/>

Special Event this month:

- Free Parent Support Group: [Difference or Disability?](#)
  - Join Dr. Dan and other parents to share ideas and challenges around language use and our understanding of different aspects of developmental differences and disabilities
  - When: Monday, December 4th

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
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### **ACEing Autism**

**Where:** Southeast DC

**When:** FALL 2023 Session

- Saturdays: December 2, 9, 16; 11:00 a.m. – 12:00 p.m. (ages 6-18)

**Register:** [Click here](#)

Join the ACEing Autism Fall 2023 Sessions. We will be offering a 50% discount for Ward 7 residents. Full scholarships are also available. Class size is limited to ensure a 1:1 volunteer/participant ratio. ACEing Autism is a private corporation with programs to support autistic individuals develop skills through sports.

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### **Ivymount Fall Educational Groups**

**Register:** [Click here](#)

Apply to participate in one of Ivymount's group programs led by expert teachers and therapists. Fall groups include the hallmark programs Unstuck and OnTarget! or Self Advocacy **AND a new Social Club!** Groups target different skills including executive functioning, flexibility, self-advocacy, transition, friendship, and social interactions. Questions?

Email [outreach@ivymount.org](mailto:outreach@ivymount.org)

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### **Partners in Policymaking**

**Where:** In Person & Virtual Events

**When:** December 2023 - 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](#).

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## **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
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### **Sensory Friendly Events**

**Where:** Washington, DC

**When:** December 2023

Click below to see upcoming shows this month!

- [Kennedy Center](#)
  - [Ford Theater](#)
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## **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](mailto:jmmckenna@childrensnational.org).

## Praise from Parents & Teens



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## **ASD Research Study**

George Washington University and George Mason University are studying 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 earn 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](mailto:aarmour@childrensnational.org) or [andilab@email.gwu.edu](mailto:andilab@email.gwu.edu)

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## **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,

- Email: [dailylivingskills@chop.edu](mailto:dailylivingskills@chop.edu)

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### **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 9<sup>th</sup> to 12<sup>th</sup> 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](mailto:jmphan@childrensnational.org).

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### **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 \$1000 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](mailto:marylandbrainstudy@umd.edu)



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](#)

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

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

"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."**

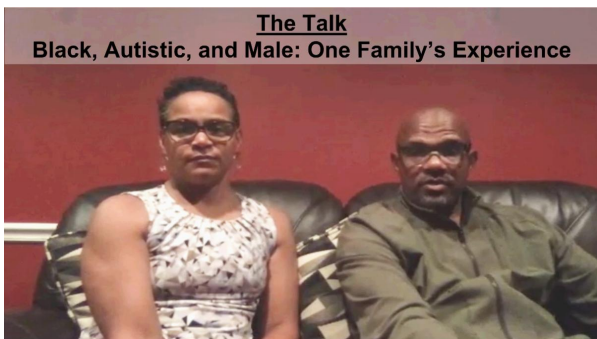
The videos made me feel less alone. --Parent

The strategies were very well explained. --Parent

**New Free Videos**  
**UNSTUCK**  
AND ON TARGET

[Playlist of all videos](#)

[Recursos para padres](#)



**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



Click here for the video

Goode, Director of the National Center for Cultural Competence and Director of the Georgetown University Center for Excellence in Developmental Disabilities.

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## 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

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### 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

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### 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.

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### 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.

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### **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/>

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### **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/>

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### **MCTransitions**

MCTransitions is a grassroots listserve 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>

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### **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

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### **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](#)

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### **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](#)

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

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