

CENTER FOR Autism Spectrum Disorders

www.childrensnational.org/CASD



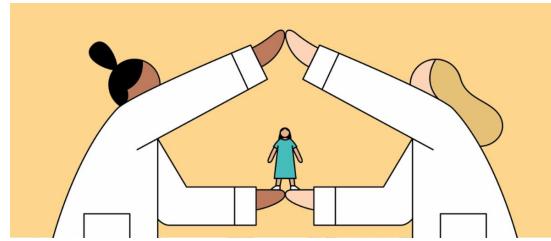
Children's National.

CASD CHAT E-Newsletter

Expanding Capacity in Autism Care

Hello Families!

Many service providers struggle to keep pace with advances in autism-specific knowledge and tend to refer children to autism specialty clinics when the diagnosis of Autism Spectrum Disorder (ASD) is in question. Unfortunately, it is in these settings where children most often wait for months or, worse, experience barriers to accessing any care at all. This has resulted in an access crisis for children and families with ASD concerns contributing to delays in diagnosis and treatment, particularly for children of color and for under-resourced families. Service disruptions and challenges related to the COVID-19 pandemic have only added to delays. As the need for autism-related services continues to grow, innovative models must be used to enhance competence among frontline medical, behavioral health, and community-based providers who currently serve these children and families on a regular basis.



Children's National has initiated a number of endeavors focused on increasing access to ASD services **through enhanced training experiences, mentorship of allied mental health and frontline professionals**, and utilization of multidisciplinary approaches. These approaches enhance the skills and knowledge of treatment providers, which allows them to accurately address the needs of autistic patients while they await more comprehensive evaluations and sometimes reduce the need for additional evaluation. We are reporting on two efforts underway currently:

1. The Center for Autism Spectrum Disorders (CASD) is hosting virtual ECHO (Extension Community Healthcare Outcomes) Autism Clinics (<https://childrensnational.org/ECHO>) aimed at building autism knowledge and competencies amongst community providers by creating shared learning forums with a multidisciplinary group of autism specialists for dissemination of knowledge and mentorship. Clinics run in 6-month sessions on a bimonthly basis and target professionals in medical, community, and educational/early intervention settings. There is no requirement for prior autism-related knowledge or training. The emphasis in learning stems from case-based discussions primarily, along with targeted autism specific didactics. *We have found good satisfaction with the program overall, as well as self-report of gains in ASD-specific knowledge and care competencies as a result of participation in ECHO. To date, CASD's ECHO Autism program has reached 290 professionals and trainees serving autistic children and their families.*
2. The Community Mental Health (CMH) CORE (Collaboration, Outreach,

Research, Equity) within the CNH Child Health Advocacy Institute (CHAI) has been working collaboratively with several other divisions, including CASD, to integrate autism evaluations into primary care sites for young children with high concern about ASD. We aim to increase capacity and access to autism services by training embedded psychologists in primary care settings in autism diagnostics. *By increasing behavioral health provider capacity and integrating in primary care, this clinic has been able to drastically decrease waits for ASD services by months to years.* Families served by the program were predominately Black (81%) or Latinx (10%), and most (87%) had public insurance. Nearly one third (32%) were not primary English speakers. An ASD diagnosis was provided in 68% of all cases. All referring PCPs surveyed indicated that they were “satisfied” or “very satisfied” with the program, that they “strongly like the integrated clinic model,” and that the program “is increasing equitable access to ASD. Currently, CHAI-supported ASD-focused embedded clinics in primary care have served 94 children and their families.

We invite you to share our CHAT and the following announcement with your health care providers, whether they are experts in ASD or new to the field, to let them know about our programs to support their work.

This CHAT was written by Drs. Annie Inge and Leandra Godoy.



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WHAT IS ECHO?

ECHO Autism, hosted by the Children's National Center for Autism Spectrum Disorders, creates a virtual learning network that aims to move knowledge, *not* people using a telementoring format that provides access to a hub of autism specialists to support providers in the community to improve care and service delivery for children with Autism Spectrum Disorder (ASD) and their families

HOW IT WORKS

- Convenient, **web-based** small-group format
- Learn and share **best practices** for autism care, service delivery, and family/caregiver support
- **Improve access** to specialized knowledge and techniques in ASD by **building local capacity** for autism care and service delivery

WHAT YOU NEED TO START:

- Internet connection
- Front-facing camera, smartphone, or tablet



BENEFITS:

- Free PLU credits available through OSSE (DC)
- Free CE credits available for speech and psychology
- Direct access to the ECHO Autism Hub Team
- Real-time **case guidance** with multidisciplinary team of autism experts
- Meet a **network of other educators and care providers** handling similar challenges

Schedule:

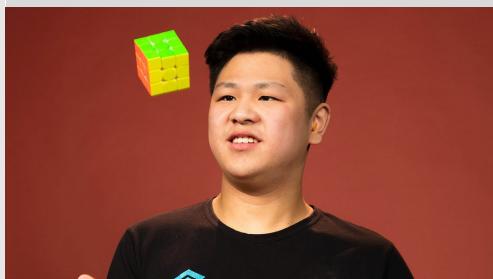
- 5:00-6:30pm EST, 1st and 3rd Thursday of each month beginning January 6, 2022

Project ECHO® collects registration, participation, questions/answers, chat comments, and poll responses for some teleECHO® programs. Your individual data will be kept confidential. These data may be used for reports, maps, communications, surveys, quality assurance, evaluation, research, and to inform new initiatives.

QUESTIONS?

Contact our research assistant Chelsea Armour at aarmour@childrensnational.org

Profiles Celebrating Neurodiversity

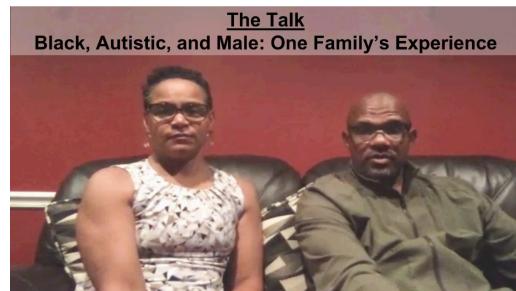


We've had the pleasure of learning about a highly gifted autistic, young man from California named Max Park. Max is an American Rubik's Cube speedsolver who formerly held the world record average of five 3X3X3 solves in 5.32 seconds! Max has set multiple world records in his career and won 297 events across many Rubik's cube competitions. Check out Max's and other speedcubers' stories on the Netflix documentary, *Speed Cubers*.

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

Click here for the
video

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.



2021 Calendar of Events

What's the difference between a 504 and an IEP?

Where: Virtual

When: March 12, 12p EST

The next Less Stress Parenting webinar will feature educational experts Jennifer Engel Fisher, M.S, Associate Director and Educational Consultant at Weinfeld Education Group, and Stephanie Frumkin, M.A. Ed., Founder and CEO at Exceptional Educational Solutions.

Does your child need more support at school to be successful? Does your child have a diagnosis with recommendations for accommodations? Understanding what options exist and how to get them can be overwhelming. Jennifer and Stephanie are the experts to help you figure out what support your child needs and how to get it for him or her. [Click here to register for this free webinar.](#)

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. To learn more about these courses, please visit his website:

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

Pathfinders for Autism (<https://pathfindersforautism.org/calendar/>) 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

NEW VIDEOS ADDED!



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."**

If you like the videos and your child attends school in Virginia, ask your school about being involved in our *Unstuck* implementation project. You can learn more about the project here:

<https://lp.constantcontactpages.com/cu/nE4K95z/UOTelementaryschool>

Relaytest
of and
patients

Last chance!

Enrollment for the study below will be ending in April. Please email Jessica Smith, jsmith9@childrensnational.org, or Laura Campos, lcampos@childrensnational.org to get involved!

Participants Needed



Using MRI Technology to Study Executive Functioning

About this study: 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.

Who can be part of this research study?

Children ages 8-13 with executive functioning (EF) challenges may be eligible to participate.



What are the benefits of taking part in this research study?

The results of this study may provide information that could help improve the accuracy and efficiency of future EF treatments. In addition, we will pay you for your time, provide free parking, and give you a picture of your child's brain.

What will participants be asked to do?

If eligible, families will be invited to one visit at Georgetown University's Center for Functional and Molecular Imaging. Visits will be scheduled at a time convenient for participating families, including weekends.

During the visit, your child will receive behavioral testing and an MRI scan. While getting the scan, your child will complete computerized tasks that are first practiced outside of the scanner. Parents may be asked to participate in an interview and complete paper questionnaires over Zoom. COVID-19 precautions are being taken and are adjusted based on public health guidance.

Contact Information

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Children's National Hospital
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Email: jsmith9@childrensnational.org

Participants Requested for a Research Study



Autistic Transgender (or Nonbinary, Agender, Gender Fluid) Young Adults

What are the goals of this study?

The Gender and Autism Program at Children's National Research Institute is studying the experiences and needs of autistic gender diverse young adults. John Strang, PsyD is the Primary Investigator for this research project.



Who can be part of the research study:

Young adults (ages 18-35) who are autistic and gender diverse (transgender, gender nonbinary, agender, or gender fluid)

What to expect:

The young adult will be asked to complete questionnaires online. We believe that the total study will take no longer than 2 hours. Participants will be compensated for their time.

What are the benefits of participating?

The results of this study may provide information that could help us to know the priorities of autistic gender diverse young adults.

Contact Information

If you have questions or would like to join the research study, please contact:

Lucy McClellan,
Clinical Research Coordinator
Gender Development Program
Children's National Hospital
Phone: 301-765-5573
Email: LMCCELLA3@childrensnational.org

Investigators at Children's National Center for Genetic Medicine Research, in collaboration with Invitae Corporation, are researching the genetic causes of human disease. If you or a family member have a known or uncertain genetic diagnosis or suspected genetic diagnosis, you may be eligible to participate in our research.



program. Please see the flyer to the left to learn more.

Pediatric Mendelian Genomics Research Center

Study of Undiagnosed and
Diagnosed Genetic Diseases.

Investigators at Children's National Center for Genetic Medicine Research, in collaboration with Invitae Corporation, are researching the genetic causes of human disease. If you or a family member have a known or uncertain genetic diagnosis or suspected genetic diagnosis, you may be eligible to participate in our research program.

If you are interested in learning more about our research program or are interested in participating, please submit a request for information here: <https://is.gd/PMGRCstudy> or email PMGRC@childrensnational.org.



Hover over
this QR code
to complete
an interest
form for this
study.

PARENT/CAREGIVER INFORMATION SHEET

Comparative Effectiveness of EIBI and Adaptive ABA for Children with Autism

Principal Investigators: Susan Hyman, M.D., Cynthia Anderson, Ph.D., BCBA-D,
Eric Butter, Ph.D., Cynthia Johnson, Ph.D., BCBA-D, Zachary Warren, Ph.D.

This information sheet tells you about a research study being conducted at several different sites including the Cleveland Clinic, May Institute, Nationwide Children's Hospital, and Vanderbilt University Medical Center. The study is called *Comparative Effectiveness of EIBI and Adaptive ABA for Children with Autism*, and is for young children with autism spectrum disorder (ASD) and their families.

What is this study about?

We are comparing two different interventions for young children with autism. The interventions are similar in many ways. Both:

- Use strategies that have been shown by research to help young children with autism learn skills (that are evidence based)
- Teach children how to better communicate and socialize
- Teach children important skills like self-help or how to not have problem behavior
- Can be modified to meet the needs of your child and your family

The interventions are different in a few ways, too:

- One intervention will have a therapist working with your child for about 20 hours per week. The other intervention has your child working with a therapist for less hours per week.
- In one intervention the therapist will work with your child on many different goals throughout the study. In the other more focused intervention, the therapist will begin by focusing on teaching your child ways to communicate better, and then may add goals to address other areas such as disruptive behaviors, sleep problems and repetitive behaviors.

Next Steps

If you want to learn more about this study, please let me know. You can let me know by filling out the form on the back and giving it back to your provider, who will give it to the research team. Instead if you prefer, you can complete this form online by scanning the QR code on the last page, and someone from the research team will contact you. You can also contact the research team directly at the phone and email listed on the next page. Writing your name on this form or contacting us will not mean that you are participating in the study, it will only mean that you are interested in learning more about the study.

It is important to know that this letter is not to tell you to join this study. It is your decision, and your participation is voluntary. If you do not wish to learn any more about the study you can just do nothing, or you can indicate "No" on the back of this form.

For more information or questions about this research, you may call Dr. Ryan Martin at (781) 364-7820, or email at Rmartin@mayinstitute.org.

STUDY Number: 00003217
Version Date: 07.19.2021

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RSRB Approval Date: 7/20/2021

We'd like to share the below information regarding the Pivotal Response Treatment project. The pivotal project was developed by the PRT team (in collaboration with the Koegel center at the University of California-Santa Barbara) and given the usefulness of PRT resources and books, we wanted to share the information on the program.

For more information, please see this link: <https://education.ucsb.edu/autism/research/prtapp>



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.

Community Resources & Events

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's COVID-19 Resources