CENTER FOR Autism Spectrum Disorders

www.childrensnational.org/CASD



CASD CHAT E-Newsletter

Gender Diversity and Autism: The Gender and Autism Program and a Research
Opportunity for Gender-Diverse Autistic Young Adults

Dear CASD friends and family,

Twelve years ago, while completing my psychology and autism-related training at Children's National, I (John Strang) was invited to become a part of the Gender Development Program as an autism specialist. The Gender Development Program is one of the first founded youth gender programs in the United States, serving transgender, gender diverse, and gender exploring youth in their diverse clinical and community-related needs since 1997. The clinicians within the Gender Development Program had noticed that a large subset of the gender exploring, transgender, and more broadly gender diverse youth coming for clinical support services were on the autism spectrum, or had many autism-related traits. They asked me to help them think about the intersection of autism and gender diversity and how best to support the many youth with these co-occurring experiences.

After completing my training and beginning as a faculty member at Children's National, it became apparent that there was an urgent need for clinical services specialized for autistic transgender youth. We founded the <u>Gender and Autism Program</u> to support these young people and their families. Along with young people and their parents, as well as key stakeholders from the community and nationally and internationally, we developed a model of care which we have begun to study. The intersection of autism and gender diversity has since become a topic of international importance. The insights that families have provided to the Gender and Autism Program <u>research initiatives</u> over the years have helped to advance the field of clinical care for the many transgender autistic people.

People have asked me over the years: "why do you think a large subset of transgender people are autistic?" To be as precise as we can be based on available findings, autism may be more than 6 times more common among transgender as compared to cisgender adults. We have no evidence for why this intersection is so common, but some have suggested that there might be a deep biological link between autism and gender diversity, perhaps related to sex hormones in very early life. On the other hand, others, including some autistic transgender self-advocates, have described how being autistic might help people to more easily express underlying gender experiences and gender diversity, as autism may free people of the social expectations and constraints that non-autistic people may experience. We do not know why so many

transgender people are autistic, but what is apparent is that autistic transgender people have an important voice in both the <u>autism and transgender communities</u>.

The Organization for Autism Research has funded us to conduct a study of the experiences, needs, and challenges of transgender and gender diverse autistic young adults in the United States and The Netherlands. This is a partnership between Children's National and the country of The Netherlands. Through this work, we hope to learn about autistic transgender young adults and their different experiences in the two countries.

If you know of any autistic transgender or autistic gender-diverse (nonbinary, agender, etc.) young adults who might be interested in participating in this study, young adults/families can contact us to learn more about the study. Study participation is fully online and takes about an hour to complete. Eligible study participants will be paid \$75 for their time. In order to qualify for the study, the young adult should be between the ages of 18 and 35, inclusive, have a pre-existing autism spectrum disorder diagnosis, and be transgender or gender-diverse.

Please find attached a study flyer below with more information about the study. For interested young adults/families, please contact Lucy McClellan at LMCCLELLA3@childrensnational.org, or call (301) 765-5573.

(This CHAT was developed by: John Strang, PsyD, Director, Gender and Autism Program, & Lucy McClellan, Research Coordinator, Center for Autism Spectrum Disorders and Gender Development Program, with the support of research assistant, Jessica Smith.)

Profiles Celebrating Neurodiversity



Martine Stonehouse, an autistic transgender woman, has become an advocate for equality in her community of Ontario. Stonehouse became an activist for transgender equality after her November 2006 case to be able to complete her gender-affirming surgery. Stonehouse says she "had a lot of fun fighting this case," and wishes her parents had been alive to see her activism.

In addition to her activism, Stonehouse is known for her love story to John Gelmon. The documentary *Transfixed* follows the couple's journey.

When interviewed by a filmmaker about Stonehouse's winning case, she says: "Yes, because of my Asperger Syndrome, I was able to 'outspeak' the government lawyers. I fought the Ontario government for eight years with a human rights case against the Ministry of Health because they delisted the funding for [gender reassignment]

surgery, just as I was about to get my approval at the Gender Identity Clinic. So I was very focused on this case. By the time we finished it, we had about 15 banker's boxes full of research that I had done for the case. I had a lot of fun with the case. It felt like a chess game, trying to outwit the opposition."

Sources:

https://www.out.com/movies/2016/5/06/meet-martine-stonehouse-trans-woman-asperger-syndrome-fighting-equality,

https://www.thestar.com/life/2008/06/21/woman_interrupted.html,

https://ourtimes.ca/article/be-bold-be-brave

2021 Calendar of Events

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.

<u>Pathfinders for Autism</u> provides a list of programs for all ages including:

- Online group for spouses/partners of adults with Asperger's;
- Information on transitioning services and Job skills;
- Online program for parents of picky eaters
- Pediatric feeding disorders in autism



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!

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

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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, Cinical Research Coordinator Gender Development Program Children's National Hospital Phone: 301-765-5573 Email: LMCCLELLA3@childrensnational.or

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.



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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 Page 1 of 2

RSRB Approval Date: 7/20/2021

Advocacy Resources

Community Resources & Events

The Drexel Autism Institute is seeking youth ages 13-29 on the autism spectrum who are transitioning to adulthood. They are also looking for these youths' caregivers and providers to participate in a study about **Team Trestle**, an application for transition planning and coordination. This virtual tool is designed to help autistic individuals meet their life goals by engaging autistic youth/young adults, their parents/legal guardians, and providers in the collaborative process of implementing and achieving goals during the transition to adulthood. For more information, check out the flyer. If you're interested, fill out the

Interest Form

at https://tinyurl.com/TrestleInterest

<u>Autistic Self Advocacy Network-</u> <u>Navigating College: A Handbook on Self Advocacy</u>

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

<u>Behavioral Directions LLC's Safety</u> <u>Teaching Protocol</u>

COVID-19 National and Local Government Resources [tinyurl.com] or email our team at sodi@drexel.edu.

The Autism Institute at Drexel University is seeking parents/caregivers OR preschool/daycare providers of autistic children aged 24-60 months who have trouble speaking and use a communication tool (i.e., PECS, AAC device). We want to better understand the use of communication tools and how collaboration occurs about communication tool use in home/school settings for minimally verbal preschool students with autism. During a 90minute focus group or interview we want to learn how teams work together to support children who use communication tools. If you are interested, please fill out the Interest Form at https://tinyurl.com/EPICfocus [tinyurl.co m] or email sodi@drexel.edu and we will contact you.

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