# CENTER FOR Autism Spectrum Disorders

www.childrensnational.org/CASD



## **CASD CHAT E-Newsletter**

## **Article Review:**

# Restricted and Repetitive Behaviors and Interests

Children with autism have restricted interests (often called intense interests) and/or repetitive behaviors. Srishti Rau, PhD provides a review on a research article on how these behaviors and interests change over time as a child grows up.



Article: <u>Developmental trajectories of restricted and repetitive behaviors and interests in children with Autism Spectrum Disorders</u>

### Why is this research valuable?

A person can receive an autism diagnosis when they have difficulty with social communication skills, demonstrate restricted and repetitive patterns of behaviors or interests (RRBs), and these difficulties get in the person's or their family's way (i.e., lead to functional impairment). A lot of research has looked at social communication skills in autism, but there is less research on RRBs, despite being a core feature of autism. It is important to study RRBs because they can get in the way of someone's social or academic functioning. For example, if a child focuses their attention on spinning objects they may miss opportunities for play and learning. Autistic individuals may find it hard to cope when their RRBs are interrupted and they may get very distressed and even lash out. Also, RRBs may interfere with the family's overall ability to get things done. For example, parents may spend extra time avoiding situations that can trigger distress for their child such as changes in plans, even if their child would

likely enjoy the new activity. Not only is it important to study how RRBs present in children with autism, but it is also valuable to study how they change over time, and what factors influence these changes (e.g., cognitive ability, severity of symptoms during early development).

## Goals of the study:

- Characterize RRBs in autistic children
- Examine how RRBs develop/change over time in autistic children
- Examine what factors predict these changes

### Who participated in the study and what did the researchers do?

- 192 children with autism and their parents
- Researchers collected information about children at 2, 3, 5, and 9-yearsold—because the same children were seen several times at different ages, this is considered a longitudinal study. They gathered information about:
  - Autism symptoms (social communication and RRBs) using a detailed autism interview with parents.
  - Children's cognitive ability by completing activities with them to assess their reasoning skills.
- Analyses:
  - Factor analysis to determine how to group/ characterize RRBs
  - Growth curve analysis was used to determine which factors predicted changes in RRBs over time.

### What did the researchers find?

- RRBs can fall into two groups:
  - Repetitive sensorimotor (RSM) examples include lining up toys, bringing toys or objects very close to one's face to peer at them, repetitive hand movements, spinning.
  - Insistence on sameness (IS) examples include becoming upset at changes to one's routine or changes to the environment that may or may not directly affect the individual, such as insisting on always sitting in the same seat or taking the same route to places.
- Changes in RRBs over time and factors that predicted these changes:
  - Parents of autistic children reported high levels of RSM over time across all ages (2, 3, 5, and 9 years old) suggesting RSM symptoms remain stably high over time.
    - Having a higher nonverbal IQ (i.e., reasoning in pictures) at 2 years old was associated with milder RSM at 2, as well as fewer RSM symptoms over time.
- IS symptoms started out at lower levels and increased over time.
  - There was no relationship between nonverbal IQ at age 2 and IS

- symptoms.
- Milder social communication symptoms at age 2 were associated with more severe IS symptoms at 2.

### What's the take home message?

It is important to study RRBs within these different sub-groups (RSM and IS) rather than studying them as one large collection of symptoms because they develop and change in different ways amongst autistic children.



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

### **Meet the Team: Additional Members**



**Liliana Acosta, Ph.D.**Psychology Postdoctoral Fellow



Michelle Wozny, RN, BSN Behavioral Health Nurse Navigator

# **Profiles Celebrating Neurodiversity**

# Steven Kapp

Steven Kapp is autistic and is a developmental psychologist at the University of Portsmouth and a Lecturer in Psychology with expertise in autism and neurodiversity. His academic background includes psychology, education, public policy, and disability studies, with additional publications in anthropology, medicine, and neuroscience reaching diverse audiences and readerships. Among other accomplishments,



he is the director of science in the Autistic Self Advocacy Network, and he substantially influenced the revision of autism's diagnostic criteria in the DSM-5. As a MA (2013) and PhD (2016) student in Human Development and

Psychology within Education at University of California, Los Angeles, he began to research and teach on autism and neurodiversity, and completed postdoctoral studies in the UK as a Research Fellow on the Wellcome Trustfunded project Exploring Diagnosis: Autism and Neurodiversity at the University of Exeter (2016-2019). His research has focused on understanding autism and means of supporting autistic people. He has a keen interest in understand autism, including how behaviors such as stimming (repetitive movements and vocalizations) and averted eye contact may serve as functional coping mechanisms.

# 2023 Calendar of Events

### **ACEing Autism**

Where: Southeast DC

When: FALL 2023 Session

Saturdays: November 11, 18; 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.

## 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

# Race for Every Child 2023: Joggin' for the Noggin'

Where: Freedom Plaza, Washington, D.C., (Or Virtually)

When: Saturday, October 21, 2023

• 8am: Opening Ceremony

• 8:45am: 5K

10am: Kids Dash

We're running or walking to advance world-class, pediatric care and groundbreaking research at Children's National Hospital. Would you like to join or support our team? Register or donate to our team or any team member here. And please spread the word! Copy and paste the link to share our team's page on social media or in email. Thank you for joining us to help children grow up stronger!

To register or donate, click here.

Contact: info@raceforeverychild.org, (301) 565-8571

### Partners in Policymaking

Where: In Person & Virtual Events

When: November 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.

## **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 <u>parent-child excursions</u>: More information on various programs can be found on his website: <a href="http://www.parentchildjourney.com/">http://www.parentchildjourney.com/</a>

## **DC Peer Programs for Neurodivergent Youth & Adults**

<u>DC Peers</u> 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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# Participate in Research

### <u>Unstuck & On Target Intervention and Imaging Study</u>

Children's National and Georgetown University are recruiting for an exciting new research study looking at how kids with autism learn. We are looking at how *Unstuck and On Target: High School* impacts learning in kids 14-18 years old with autism. This intervention is designed to promote executive functioning skills including flexible problems solving, self-advocacy, and planning. Participation involves MRI scanning, cognitive assessments, and the treatment program.

If interested, please contact Andrea Lopez at alopez4@childrensnational.org.

# 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 <a href="mmckenna@childrensnational.org">mmckenna@childrensnational.org</a>.



## **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: <u>aarmour@childrensnational.org</u> or <u>andilab@email.gwu.edu</u>

# **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: <u>dailylivingskills@chop.edu</u>

## 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 <a href="mailto:jmphan@childrensnational.org">jmphan@childrensnational.org</a>.

# 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

# **Unstuck & On Target Resources**



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."

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



Click here for the video

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.

<u>Click here</u> 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 <u>DC Autism Collaborative</u> (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 <u>visit the website here</u> 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! <a href="https://pathfindersforautism.org/calendar/">https://pathfindersforautism.org/calendar/</a>

### 20+ free resources available to view anytime, anywhere!

Enjoy these <u>information-packed free webinars</u> 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 <u>DC Autism Parents (DCAP)</u> 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**

<u>Autistic Self Advocacy Network-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**

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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