CENTER FOR Autism Spectrum Disorders





CASD CHAT E-Newsletter

Elopement and Wandering

Wandering, running off, or what we clinically call

"elopement" is a major concern for many families of children with autism and other developmental disabilities. Roughly half of autistic children will attempt to elope at least once in their lifetimes. Children most commonly elope from home, school, or stores. The children who are most likely to elope have more social difficulties and lower cognitive



abilities, as well as more challenges regulating emotions and coping with new situations. Children most commonly elope because they enjoy running or because they see something they are excited about. However, elopement can also be triggered by anxiety, overload, and a need to escape. Although the vast majority of children who elope are safely found and recovered, elopement does increase the risk for drowning, serious injuries, or being missing long-term. Unfortunately, most families say that they have gotten little or no guidance from providers about how to manage elopement and keep children safe.

What can families do if their child tends to "run off" or elope?

Families often focus on how to *respond* when their child elopes, but the most important and effective steps to take are to *prevent* a child from eloping in the first place. The <u>AWAARE Collaboration</u>, sponsored by the National Autism Association, has helpful information and free resources available for families to help with elopement.

- 1. Increase safety at home. Adding simple visuals, like a stop sign on the door, can help. Have your child practice stopping and holding an adult's hand every time you leave the house. Simple safety mechanisms, like out-of-reach deadbolts or chains, can help, along with adding a shop bell or alarm system to alert you when a door is opened. If you have a pool at home, be sure to place fencing around it.
- 2. Take notes about when your child elopes. Many children have particular triggers or patterns to their elopement. After your child elopes and is safe again, note where you were, how your child was feeling, and what was

happening. Figuring out these patterns can help you learn when your child elopes and watch carefully at those times. You can also provide supports to address their needs, like noise-cancelling headphones for children who are sensitive to noise, or a preferred toy or activity for times when they have to wait.

- 3. Increase safety in the community. For children who tend to elope in public, practice specific behaviors that make eloping less likely. For example, you can practice having your child hold your hand or hold onto a shopping cart, and give them praise or a small reward each time. Practice stopping and looking for cars every time you enter a parking lot or cross a street. Praise your child for doing these behaviors with you, labeling the specific behavior (e.g., "Wow, you did a great job stopping and looking for cars!"). Some families also find safety devices, such as backpacks or bracelets with a tether, to be useful.
- 4. **Engage community members**. Tell neighbors, schools, babysitters, and others that your child may run off, and make sure they know to contact you and emergency personnel if they see your child alone. It can be helpful to provide neighbors with a picture of your child with your contact information on it. You can also ask your local police department about registering your child, so they know how to respond in case your child is lost. Many departments also participate in *Project Lifesaver*, which is specifically geared to help families of those with autism and other conditions who tend to wander.
- 5. Practice with your child what to do if they are lost . If your child can speak, practice saying their name, address, and phone number. Help them identify safe people to approach if they are lost a good rule to give is "someone in a uniform" or "a grown-up with kids." For children who are not speaking or who struggle to use words when upset, it can be helpful to have an identification bracelet, a shoe tag, or simply a card pinned to their shirt. Children who use a voice output device (or "talker") can also have identification information programmed into their talker.
- 6. Enroll your child in swimming/water safety lessons. The overwhelming majority of deaths related to elopement (around 90%) are by drowning. Teaching a child how to swim and the skills for being safe near water, such as never going in water without an adult, can be lifesaving. Many local pools, community organizations, and county recreational programs offer adaptive swimming lessons for children with disabilities.
- 7. **Develop a safety plan**. Consider taking a daily picture of your child, which can be shared with emergency personnel if needed. Provide anyone working with or caring for your child with a safety plan that includes contact information, a photo, key medical information, warning signs, triggers, and ways to help your child de-escalate to avoid elopement. Develop a plan of who can help in an emergency and key search points near locations like home and school, where your child is likely to be.
- 8. **Consider a tracking device for children who elope often.** Tracking devices, like GPS, are usually a last resort. They can be expensive, are often uncomfortable to wear, and need to be charged or have batteries changed frequently. Tracking devices also tend to have a limited range, so it's important to follow all the other steps as well, and not simply rely on the tracking device. Your local police department or *Project Lifesaver* program may have options for free or subsidized devices.

What To Do When and If Your Child Elopes

It is incredibly stressful and frightening if your child elopes, and you are unable to quickly find them. Having a safety plan, like the ones available through the <u>AWAARE</u> <u>Collaboration</u>, can help you to respond quickly and effectively. If your child does elope:

- Seek help from others as soon as possible, and be open about child's strengths, challenges, and how they may respond under stress. Do not wait; call 911 immediately. Be clear that your child has autism, and that this need to be treated as a critical case.
- Search high risk areas first. Start with the highest threat areas, including nearby water, busy streets and intersections, train tracks, or busy parking lots/garages. From there, move to places that your child likes or would be interesting, exciting, or comforting to them. Get others to help, if possible.
- 3. Show a recent photo to emergency personnel and to anyone nearby who can help. If you are in a crowded place, when calling out for your child, call their name, but also add what they were wearing. For example: "Jayden! Blue shirt and black shorts!". This can help people around you to immediately notice that you are looking for a lost child and begin helping you search.

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



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

Profiles Celebrating Neurodiversity



Lydia X. Z. Brown

"Among many other things, I am a writer, public speaker, educator, trainer, consultant, advocate, community organizer, community builder, activist, scholar, and attorney."

Brown has worked to address and end interpersonal and state violence targeting disabled people, especially those who are marginalized. They are a member of the Autistic Women and Nonbinary Network and have had an impactful journey in disability advocacy. Learn about Brown's impact:

- Fund for Community Reparations for Autistic People of Color's Interdependence, Survival, and Empowerment
- <u>Bearing Witness, Demanding Freedom</u>, the Living Archive and Repository of the Judge Rotenberg Center's Abuses.
- All the Weight of Our Dreams: On Living Racialized Autism.
- <u>We The Future Campaign</u>.
- I Identify As Me

Additionally, they are an adjunct lecturer and core faculty in the <u>Disability Studies</u> <u>Program</u> and the <u>Women's and Gender Studies Program</u> at Georgetown University, and as an adjunct professorial lecturer in the <u>American Studies Program</u> at American University's Department of Critical Race, Gender, and Culture Studies.

Photo and text from Lydia's website.

2023 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, <u>click here</u>.

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</u> <u>excursions</u>: More information on various programs can be found on his website: <u>http://www.parentchildjourney.com/</u>

Summer Programs for Neurodivergent Youth & Adults Where: DMV area When: Summer 2023 **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.

Here's the lineup:

Adult Programs (mid-June through mid-August)

- <u>Not-So-Typical Happy Hour [dcpeers.us4.list-manage.com]</u> | virtual | 1st & 3rd Saturday | 5:30-6:30 | free
- <u>Neurodiversity Support Group [dcpeers.us4.list-manage.com]</u> | hybrid | 2nd & 4th Thursday | 6:30-8 | free
- <u>Women and Non-Binary Persons' Neurodiversity Support Circle</u> [dcpeers.us4.list-manage.com] | virtual | biweekly on Wednesdays | 6:30-7:30 | free
- Registration coming soon for:
 - Adult Meetups around town
 - Camping Trip (!!)

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!

In partnership with educators, autistic youth, and their families, autism experts from Children's National Hospital have developed an upward extension of the schoolbased *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 problemsolving, 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.



ASD Research Study

George Washington University and George Mason University are studying brain development in autism. As part of the study, participants play childfriendly 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 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 \$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: <u>marylandbrainstudy@umd.edu</u>

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."





Click here for the



Recursos para padres

AND ON TARGET

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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

video

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 <u>"Together We're Better" (TWB)</u>. 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. <u>Visit the website here</u> 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! <u>https://pathfindersforautism.org/calendar/</u>

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</u> <u>Advocacy</u>

Resources on Anti-Racism

<u>Spectrum Support's Social Stories on Racism</u> <u>ASAN's What is Police Violence?: A Plain Language Booklet</u> <u>@TheMorganCruise Worksheets for Black Children</u>

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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