

Center for Autism Spectrum Disorders

www.childrensnational.org/CASD



Children's National: CASD CHAT

Introduction

Seasons Greetings, and welcome to another exciting issue of CASD Chat!

In this issue, we share how CASD is helping underserved and underdiagnosed children through our Patient-Centered Outcomes Research Institute (PCORI) funded project, provide a few more tips on how to relax and unwind during the holiday season in CASD Cares, feature upcoming community events in our Calendar of Events, and share recent articles featuring CASD Faculty.

CASD Research Report

Underserved and Underdiagnosed: How CASD is Helping the Community

Over the past three years, researchers at CASD have been working on a project titled, "A Community-Based Executive Function Intervention for Low Income Children with ADHD and ASD." The project is funded by the Patient-Centered Outcomes Research Institute (PCORI), an independent organization that promotes patient-centered research as a means to make real-world change. The project, led by Dr. Laura Anthony and Dr. Lauren Kenworthy, has led to revolutionary findings in health care disparities among children with neurodevelopmental disorders. Our Community Outreach Coordinator, Yetta Myrick, serves as the project's Stakeholder Advisory Board (SAB) Chair and presented preliminary findings at this year's PCORI Annual Meeting in National Harbor, Maryland. The SAB consists of parents, developmental pediatricians, teachers, researchers, and community members who all equally contribute to guiding the project toward meaningful outcomes.

Dr. Kenworthy and Dr. Anthony discuss their experience leading this project here: http://www.pcori.org/blog/changing-course-research?utm_source=social.



Learn about the study:

THE STUDY



Compared two executive functioning interventions



21 Title One schools in the Washington D.C. area



Stakeholder input steered community engagement



Intervention delivered by school personnel

OUR PARTICIPANTS



Under 30% of participants were White, non-Hispanic



12 different languages were spoken at home



Annual net income was as low as \$9,000



Average parent education was 15.2 years

PRELIMINARY FINDINGS

Undiagnosed

&

Underserved

- Diagnostic evaluations were available in English & Spanish
- Discovered about 50% of participants lacked a clinical diagnosis of ADHD and ASD
- CASD researchers diagnosed these children through the study, qualifying them to receive EF treatment
- Trainings were community-based and accessible via public transportation
- 77% of parents attended at least one parent training
- 95% of families returned for post testing

CASD Cares

How to Relax and Unwind During the Holidays

Your family has navigated Thanksgiving, and now you are wondering what you are going to do with your child over the winter break. How do I keep my child engaged during the holidays while still giving him/her a break from the demands of everyday life?

Here are three tips to help your family enjoy the winter break.

1. **Embrace the season.** Just because your child has ASD does not mean that you and your family should sit out the festivities. There are many experiences for your family to be a part of and enjoy. Try planning and thinking creatively about how you can help your child to access these often crowded experiences in a fun way. Maybe you visit during the week instead of on the weekend, if your schedule permits. Maybe you create a social story or show your child the event website to help them anticipate what's to come. Maybe you can prepare a special treat that your child loves and bring it along with you for the adventure. Go ahead and join the masses as they walk or drive through winter lights displays. It is a great time to take advantage of human kindness that springs forth this time of year and have fun! 'Tis the season.
2. **Share the Moment.** When families and friends come together for the holidays, many share gifts, compliments, and other kind gestures. Often, children with autism have difficulty understanding and identifying the thoughts, feelings, and intentions of others. These "Theory of Mind" difficulties may make it challenging for your child to reciprocate in an appropriate manner. Imagine your child receiving a gift of food that they do not like ("*Here, take a cookie!*"), or a subtle

compliment from a relative ("*What a nice sweater you are wearing!*"), or a comment referencing the environment ("*Oh look, isn't the snow beautiful?*"). Take these opportunities to help your child navigate the social maze of the holidays. When giving-and-receiving, simply saying, "Thank you," is the first step to thinking about others' well-meaning.

You may also want to think about ways to incorporate your child into the activities happening around your home, such as cooking or baking. If your child is interested in cooking, you can create a functional cooking session by talking about the recipe with them. Ask about what items are needed, practice cracking eggs, emphasize kitchen safety, and more. This is a fun way to have family time without the pressure. All the language you need is right there on the recipe! Please don't forget to praise your child along the way. Sharing the moment can be a win-win for all.

3. **To Plan or Not to Plan?** Remember last month when we talked about setting aside "me time" for yourself? Well our children need down-time too! It's okay for your child to take a break from school, therapies, and the everyday routine to avoid burnout. In addition, your child's teachers and therapists need time for respite, self-care, and rejuvenation. Allow your child to have down-time, but also create spaces of structure. Support your child by creating visual First/Then schedules using a dry erase board. An example of a semi-structured schedule is to write something like, "First: Clean your room, Then: Your choice." An open-ended choice may be overwhelming for your child. If that is the case, you can list two or three preferred activities.

Additionally, you can prepare your child by preemptively discussing the family's plans for winter break. If you have the flexibility, you can empower your child by planning some of the activities together. Lastly, remember to prepare your child for the transition back to school by ensuring that they maintain (or return to) a regular sleep routine. If you find that your child's bedtime has become later than usual over the break, simply work to move up bedtime a half hour earlier each night until things are back to normal. If all doesn't go as planned, that's okay! Winter break is a time to have fun and relax.

CASD in the Media

Check out these great articles featuring CASD Faculty Members!

[The Atlantic: The Link Between Autism and Trans Identity](#)

[PCORI Blog: Changing the Course of Research](#)

[Spectrum News: Supports help some children with autism socialize at school](#)

[Spectrum News: New clinical guidelines address gender dysphoria in autism](#)

You May Be Interested...

Bo Bigelow, a father who "quit his law job to stay home with his kids", reflects on life with his children, specifically surrounding his special needs daughter, Tess. Check out

this 13-minute Podcast, "A Test We Actually Enjoy Taking", about getting Tess evaluated for autism: <http://www.portlandrootsmedia.com/strongerpodcast/2016/6/15/74-a-test-we-actually-enjoy-taking>

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