Center for Autism Spectrum Disorders

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Children's National

Children's National: CASD CHAT

Introduction

Greetings from CASD!

In this issue, you will learn about our newest research project, as well as ASD-centered tips on how to find passion in our lives. We also share local sensory-friendly events and recognize CASD Medical Director, Haniya Raza, DO for being voted as one of DC's Best Doctors in Washingtonian Magazine. Welcome to another exciting issue. We hope you enjoy reading it!

CASD Research Report

Looking Beyond Diagnosis: the RDoC Difference

Our newest project, launching this month, is a collaboration between CASD and Georgetown University's Developmental Cognitive Neuroscience Laboratory (DCNL). The project, "Executive Function Across Pediatric Psychiatric Disorders," is a part of a new research initiative to better understand the brain science behind the varying types and degrees of behaviors we see in those with neuropsychological disorders. The NIH-based movement, known as the Research Domain Criteria Initiative (or RDoC), is intended to encourage a novel approach to clinical research.

RDoC
Research Domain Criteria Initiative

Click to learn more!

To learn more about these exciting new efforts, we went to the study's primary investigators: Drs. Lauren Kenworthy and Madison Berl of Children's National, and Dr. Chandan Vaidya of Georgetown University.

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1. What makes the RDoC research framework unique?

LK: We have a problem in the way that we understand and treat a lot of disorders, including autism. We haven't made the kind of progress on treatments, medical or behavioral, that we want. There's a whole important group of researchers who think that our lack of progress could be because we're limiting ourselves to diagnostic categories. Currently, you are either going to fall into a diagnostic category or not. The really cool thing about the RDoC design is that it allows us to move away from treating labels and move towards treating the problems that parents are reporting about their kids.

CV: The RDoC approach comes from the recognition that across diagnosis there are these common treads that run. For example, anxiety; anxiety can be present across ADHD, autism, anxiety disorders, depression, and many other psychiatric disorders in varying degrees. From a scientific point of view, what the RDoC method aims to do is to get scientists to think about how we can measure a behavior that is running across conditions and then categorize it in the brain. Understanding the brain circuitry of anxiety, executive functioning, or other psychological processes, will then allow us to determine best treatments.

LK: Once we understand the brain mechanisms that drive a child's behaviors, we believe that we will be better at developing effective treatments that target specific behaviors, regardless of diagnosis.

MB: For autism, this notion is clear to see in social difficulties. Among children who are clearly on the autism spectrum, there are many different reasons a social interaction could go awry. A child with ASD may have a social interaction go poorly because he is anxious about the situation, because he is inattentive/distracted and isn't focusing on the situation, and/or because he doesn't understand the social structure of conversation and isn't maintaining the reciprocal back-and-forth. All three factors, or sometimes two, or maybe just one, could be leading to this social breakdown. These types of situations remind us that there can be different explanations behind the same behavior.

2. What do you hope to achieve through this project?

LK: The problem we're tackling is that, currently, we lump kids into categories that don't give us enough information to drive a good treatment plan. The solution that we are aiming for is to be much more precise in identifying specific patterns of problems within kids that inform both which treatments to use and the order in which to use them. In more medically-based disorders, this is called precision medicine or individualized medicine.

CV: In the past, we've done studies where we've tried to figure out what the treatment is doing in the brain. After studying ADHD and stimulant medication, we now understand the underlying neurochemistry much better. We are able to relate the behavioral symptoms to the efficacy of the stimulant medication.

MB: We already have good brain science to make treatment decisions for our simple, uncomplicated populations, such as those with ADHD only. Now, we are taking it up a level to look at more complex populations that experience similar behavioral issues.

CV: This grant will allow us to know what to measure in the brain for future treatment outcomes. That in itself is a big issue. We don't know where in the brain the behavior manifests. We are identifying the brain circuitry that is associated with a pattern of behavioral issues. Once we identify the brain circuitry and establish how to measure an

individual's behavioral characteristics, we'd like to get to the point where we can assess the effectiveness of treatments.

3. What does this project mean to you personally?

LK: What makes this project particularly exciting and, frankly, unique is that we are taking a true team approach. What we know as a team is that the answers don't ever lie just in what you see in the brain or just in what you see in the clinic. We have to bring that knowledge together to really understand the primary mechanism of the behavioral problems.

CV: From a neuroscience point of view, I've personally been so disappointed that after 15 years in this field, what neuroimaging has basically done for disorders is really describe them (what a deficit looks like in the brain). But there's been no future of what we can now do with this knowledge. For me, this project is particularly exciting because it is the promise of going towards making a difference in the context of treatment in a way that I think is more realistic than anything we've ever had. From a personal point of view, I feel very optimistic and hopeful that this will make a difference in making informed treatment decisions and producing positive outcomes.

LK: What Dr. Vaidya is talking about is taking this neuroimaging science (that's developed fairly recently) and making it relevant to the clinic. And that makes it relevant to us as clinicians, as parents, and as people who see kids who have remarkable capacities that aren't being realized because we don't have exact treatments.

MB: This is a very real world approach. We want the variability, we want the complexity, we want your specific child who is unique to themselves. It embraces the saying that "You've met one person with ASD or ADHD, which means that you've only met one person with ASD or ADHD." Yes, there are commonalities, but we are appreciating the complexities and differences between behavioral characteristics so we can help *your* child - not just help ASD or ADHD as disorders. And that's what's exciting. The fact that we need large numbers for this project is important for the community to know - it won't succeed without participation. Because we want everyone, we really need everyone in order to get a complete understanding [of the neurological characteristics].

LK: We need a lot of people, and we're listening to you. This is the time when we are going to take what YOU say your child's profile is and try to understand how that informs what goes on in the brain.

To learn more about the RDoC study:
Please contact Meredith Powers at mdpowers2@childrensnational.org or 301-765-5771.

CASD Cares

Finding Your Passion

What is passion? Merriam-Webster describes passion as "a strong feeling of enthusiasm or excitement for something or about doing something." When our loved one with autism is first diagnosed, many of us get swept up into the world of autism and try to do everything we can to obtain appropriate services and supports. There is nothing wrong with this, but our everyday routines can lead us to often forget what is most important to us as parents or caregivers. This in no way takes away from the work that we do for our children. However, we must find ways to hold on to our own identities.

Here are three tips to help bring passion back into your families' lives.

1. **What is your passion?** What were you passionate about before your child was diagnosed or even before your child(ren) were born? What did you do for fun? Did you love hiking, doing yoga, playing basketball, reading, visiting museums or simply taking a leisurely walk? Find time to focus on what brings joy to your life. This in and of itself can be a form of self-care. It is imperative that you find time for yourself to be passionate for something that is outside of your child. Alternately, if you don't think devoting this time is possible right now, find something that you can be passionate about within the realm of you advocating for your child. Do you find organizing and managing your child's records fulfilling? Have you started a group for other parents to share their experiences with one another? The journey can be long, but finding that simple pleasure and joy in your life can be your saving grace.

2. **What is your child's passion?** What does your child really love to do? Does your child love to draw, listen to music, study trains, or go to the pool? Even as a child's interests come-and-go, it can still be beneficial to connect his or her interests with future careers. The possibilities are endless. It may be difficult for some of our children to envision their futures. However, brainstorming ideas (and eventually coming up with plans to put these ideas into action) can help prepare your child for adulthood. Find outlets and expose your child to an array of opportunities related to their passions. Never force it; rather, help your child develop their interests. This will enable them to turn their passion into a set of specialized skills for adulthood.

3. **What is your shared passion?** What are things you and your child can be passionate about together? At first, you may need to focus on things your child likes to do. Over time, try exposing your child to some of the things you are passionate about too. Do you love to read? Visit a library together. If you think your child won't be open to totally new experiences, try compromising. Maybe you do something your child likes first, then take them somewhere you enjoy. Be creative and think outside the box. The more you enjoy new experiences together, the more dynamic your relationship with your child will be.

CASD in the Media

CASD Medical Director, Haniya Raza, DO featured as one of DC's Very Best Doctors for 2017!

Talking About Men's Health - Helping Children Reach their Potential: Learning What Works

You May Be Interested...

The Autistic Self Advocacy Network (ASAN) is now accepting applications for the 2017 Autism Campus Inclusion (ACI) Summer Leadership Academy! To learn more and apply, please visit: http://autisticadvocacy.org/2017/01/aci-2017-applications-now-open/

Dr. Dan Shapiro is hosting a ten session workshop for parents, ***An Individualized Approach to RAISING YOUR CHALLENGING CHILD***. To learn more and register, please visit: www.parentchildjourney.com.