

McPartland Lab

WINTER NEWSLETTER



DIRECTOR'S WELCOME

BY DR. JAMES MCPARTLAND

Dear lab extended community,

A new year has arrived, and, with it, an updated edition of our lab newsletter. In this issue, we provide many practical tips for recognizing and managing anxiety. This is a common challenge for people on the spectrum, and we hope this advice from an experienced member of our clinical team can be helpful. We also highlight one of our community partners, The Color of Autism Foundation. This edition of the newsletter provides more information about a new line of research in the lab. We have developed a set of tools and strategies to help us include people with autism and intellectual disability in our research. We are very excited about this opportunity to make our research more inclusive. You'll meet and learn about two of our research fellows, Sara and Bridget, and we'll share some ideas for having fun about town while the weather is frosty.

We look forward to hearing from you and, hopefully, seeing you around the lab!

Sincerely,
Jamie McPartland

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MANAGING ANXIETY

BY DR. JULIE WOLF

If your child experiences anxiety, they are not alone! Research suggests that around 40% of autistic individuals experience significant anxiety. Some features of autism, in some individuals, may be in response to anxiety. For example, some individuals seek sameness, familiarity, or routine as a way of making their environment more predictable and thus less anxiety-provoking. Some autistic individuals tell us that they avoid making eye-contact because they find it anxiety-provoking. Further, in some individuals, sensory-seeking behaviors may serve the function of soothing anxiety. Interestingly, many individuals who have anxiety but not autism also show these same behaviors.



Anxiety can also co-occur with autism, making existing social challenges more pronounced. For example, some autistic individuals experience social anxiety. In addition to having difficulty building peer relationships due to autism, they may feel anxious about doing so.

When anxiety is causing an individual distress or is interfering with their functional performance or attainment of their goals, the following strategies are suggested to alleviate anxiety:

- **Create predictability.** Sometimes anxiety can be triggered by not knowing what to expect in a situation. Therefore, making the environment as predictable as possible can help to alleviate anxiety. Some strategies for increasing predictability include:
 - *Visual schedules and planners:* For children, posting a visual schedule of the day's activities or a to-do list of upcoming tasks can help them to know what to expect. For adolescents and adults, keeping a personal planner with appointments and tasks for the day can have the same effect.
 - *Visual timers:* Timers can be helpful to give a child a visual representation of how long a task will last. This can also reduce anxiety around transitioning from one task to the next because the timer provides a visual indication of when the transition will take place.
 - *Clear start and end points:* Any strategy that makes it clear when a task will start and end can increase predictability. For example, you might provide your child with a "to-do" box with tasks that need to be completed, and a "finished" box where they can place their completed work. This makes it clear that when the "to-do" box is empty, the work is done. Visual sequence strips that show each step needed to complete a task can also help a child to anticipate when a task or activity will be complete.

- **Increase emotion identification.** Some autistic individuals may have difficulty identifying their own emotions. Learning to do this is an important first step in being able to manage anxiety. You can help your child to identify emotions through a variety of strategies:
 - *Link emotions to bodily sensations:* Talk with your child about how to recognize anxiety in their own body (increased heart rate, rapid breathing, perspiration).
 - *Model emotion labeling:* Model for your child by labeling and describing your own emotions (e.g., “I am feeling nervous because I have a big presentation at work today. My heart is racing!”)
 - *Use visual strategies:* Visual strategies such as emotion thermometers and visual rating scales can be used to help children identify and communicate their level of anxiety. For example, they could color or mark on a picture of a thermometer how high their anxiety is at a given moment. Or they could simply point to how they are feeling on visual rating scale. If you search Google images for “feelings thermometer” or “emotion rating scale” you will find many examples of visual methods of communicating feelings.



- **Teach self-advocacy.** Once an individual is able to recognize their own heightened anxiety, a next step is to promote the ability to advocate for their own needs. For example, children can be taught to ask for a break from activities that are causing anxiety. Minimally speaking individuals can be taught to use a sign for “break” or have a “break” button on their AAC device for this purpose. Autistic adults who are working or enrolled in higher education are encouraged to talk to their supervisors, employers, or college disability office to request accommodations for anxiety.

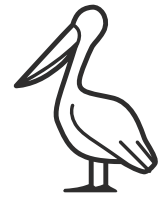


- **Implement coping strategies.** Finally, individuals with anxiety can learn various coping strategies for managing their anxiety. Some strategies include using mental imagery (e.g., picturing something relaxing), breathing techniques, and guided meditation. There are many apps and YouTube videos available that provide guided meditation and relaxation exercises. Some individuals may be able to teach themselves these strategies, while others may benefit from working with a therapist or counselor to learn these techniques.





STUDY SPOTLIGHT: AUTISM AND INTELLECTUAL DISABILITY



What is the goal of the study?

During the past few years, autism researchers have increasingly discussed the need to recognize and include the subgroup of autistic people who also have intellectual disability. Throughout the history of autism research, this group has been largely excluded from brain research because of challenges understanding or tolerating experimental procedures. For this and many other reasons, in January 2022, an international panel of autism clinicians and researchers and autistic people published a call for reconceptualizing the autism spectrum to highlight this group. They suggested adoption of a term, profound autism, to refer to autistic people with very low IQ scores and high support needs.

How do we accomplish that goal?

A new research program in our laboratory is focused specifically on this population. We have developed a specialized set of procedures and designed a customized room to help individuals with profound autism participate in research. We are hopeful that these new approaches will allow individuals with limited verbal expression or comprehension to participate in our research studies and enable our scientific discoveries to be relevant to all autistic people.

Who can participate?

As we continue with this study, we ask for your help. If you have a child between the ages of 3 and 17 with an IQ below 60, please consider partnering with us in this important research. We will work together to understand how we can design a research experience to maximize your child's comfort and enjoyment. We hope that this new approach can help usher in an era of improved inclusivity in autism research.



Interested participants can contact Bela at 203-737-3439 or autism@yale.edu.



IN THE COMMUNITY: THE COLOR OF AUTISM FOUNDATION

In the realm of autism research, a significant opportunity lies in understanding and addressing the disparities in care and services in underserved communities. These disparities often manifest as limited access to essential services, prolonged waitlists, and inadequate mental health and mindfulness support for parents.

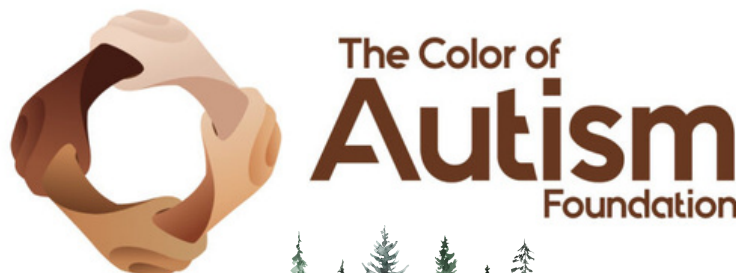
Autism researchers have a unique opportunity to make a meaningful impact in these communities. By adopting a culturally responsive approach, they can delve deeper into the home-based challenges families face. This approach involves moving beyond conventional participation incentives like stipends, which may not fully address the real needs of parents and their children. Instead, tailoring research incentives and support to meet the specific needs of the community can have a lasting impact.

Partnerships are crucial in this context, not just for effective recruitment but also for supporting the organizations involved in these efforts. Allocating funds to assist partner organizations is a significant step in ensuring that research benefits the community holistically. The Color of Autism Foundation sets an example in this regard, partnering with researchers to provide essential services like parent training and support groups. This approach not only facilitates culturally sensitive research but also offers practical benefits to study participants.

Through training and support, the foundation empowers parents to be effective advocates and data collectors for their children, fostering a deeper understanding of autism. This empowerment is crucial for parents to embrace and support their children's unique needs, thereby nurturing self-love and self-advocacy in children on the spectrum. The foundation's work underscores the importance of researchers understanding and embracing the community's needs, thereby leaving a lasting and positive impact in the lives of families supporting their autistic loved ones.

The Color of Autism Foundation is a non-profit organization dedicated to raising awareness and providing support to African American families affected by autism spectrum disorder. Founded by Camille Proctor in 2009, the foundation emphasizes educating and assisting these families through culturally competent resources. It focuses on empowering parents with the knowledge and tools needed to be the best advocates for their children, aiming to demystify autism in the African American community and improve early detection and intervention. The foundation's efforts contribute significantly to creating a more inclusive and understanding environment for on the autism spectrum.

<https://thecolorofautism.org>



MEET THE LAB!

SARA SILBER

Introduce yourself! What is your role at Yale?

My name is Sara, and I am a first-year Sparrow Fellow. I grew up in Bethesda, Maryland and graduated from Franklin and Marshall College in 2021 with a BA in Psychology and minor in Environmental Studies. My favorite part of the job is getting to know all of our incredible families and participants! Outside of the lab, I enjoy spending time in nature, with my cat (Willow), and going to baseball games.

What did you do before you joined the McPartland Lab?

Prior to joining the lab, I worked with Dr. Suzy Scherf in the Lab of Developmental Neuroscience at Penn State University. In the lab, I got to work with children and adolescents ages 6-17 years old and their parents. We researched how puberty and emotions are related to social experiences through behavioral assessments and brain scans. We also researched social perception in autistic adolescents through a video game intervention and eye-tracking. I also volunteered with Crisis Text Line, supporting individuals in the midst of crisis, which solidified my interest in pursuing a career in clinical psychology.

What made you interested in working in this field?

I initially became interested in this field by growing up with autistic individuals. In college, I explored this interest by volunteering with a couple of summer camps and sports programs for autistic children, designed to promote motor and social development. College coursework, an internship at a behavioral health center, and senior project exploring how nature can be therapeutically beneficial for autistic children solidified my desire to pursue a career in this field.



BRIDGET WALICKI

Introduce yourself! What's your role at Yale?

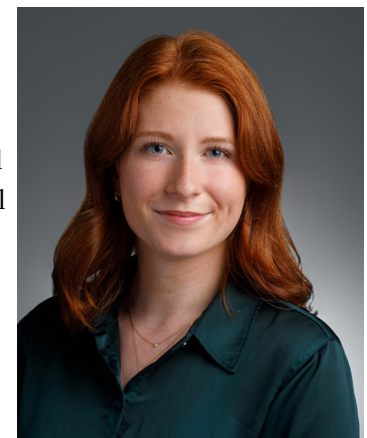
My name is Bridget, and I am a first-year Sparrow Fellow. I grew up in Ridgewood, NJ, and attended Lehigh University in Bethlehem, PA. I graduated in 2022 with a B.S. in Behavioral Neuroscience and received my masters in Healthcare Systems Engineering the following year. One thing I love about the McPartland Lab is that our studies benefit participants and their families both directly by helping them access the services they need and indirectly by advancing our understanding of autism. Outside of work, I love to cook and travel with friends and family.

What did you do before you joined the McPartland Lab?

Before joining the lab, I was a research assistant in Dr. Nancy Carlisle's Memory and Attention Lab at Lehigh where I studied how the brain learns to ignore distracting information. I served as a peer writing coach for a variety of courses, including history, biology, and engineering.

What made you interested in working in this field?

I first became interested in this field while working at an outdoor summer camp for autistic kids. Building relationships with the campers and their families and seeing the positive impact I had on them (and vice versa!) solidified my desire to work with autistic people.



FUN WINTER ACTIVITIES IN CONNECTICUT

Powder Ridge Mountain Park and Resort: Middlefield, CT

Powder Ridge Mountain Park and Resort has a range of snow activities, including skiing, snow boarding, snow tubing, and a kid's snow play zone.

Powder Ridge Mountain Park and Resort

Connecticut Science Center: Hartford, CT

The Connecticut Science Center includes exhibits for children of all ages related to physics, engineering, life sciences, and more. They will be hosting a Sensory Friendly Day Feb. 11 from 10-4 and will continue to host these throughout the year!

Connecticut Science Center

Ice skating at Ralph Walker Ice Rink: New Haven, CT

Check out their Facebook page for hours and events!

Ralph Walker Ice Rink

Mystic Aquarium: Mystic, CT

The Mystic Aquarium is home to marine mammals, fish, invertebrates, and reptiles. The Yale New Haven Health Family Lounge and First Aid Center in the aquarium serves as a sensory-friendly quiet room and is located within the Main Gallery.

Mystic Aquarium

KidsPlay Museum: Torrington, CT

The KidsPlay Museum offers Sensory friendly playtimes Feb. 25th and March 22nd. Enjoy the Museum in a calmer, quieter environment without the noise, crowds, and stimulation of a typical day!

Sensory Friendly Playtime

The Prospector Theater: Ridgefield, CT

The Prospector Theater offers sensory friendly screenings where they provide sensory bags, weighted lap pads and strobe-canceling glasses.

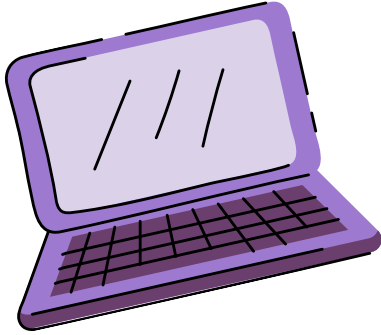
The Prospector Theater

Connecticut Historical Society: Hartford, CT

The Connecticut Historical Society in Hartford has created Sensory Bags with helpful "tools" such as sunglasses, headphones, timers, and other useful items. The bags are free and can be obtained at the admissions desk upon arrival.

Connecticut Historical Society

LEARN MORE ABOUT OUR LAB!



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OUR WEBSITE



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PARTICIPATING?
FILL OUT THIS
FORM!



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